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COVID-19 Pandemic Impact on Patients, Families and Individuals in Recovery from Substance Use Disorders

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About the Report

This report from the Addiction Policy Forum sheds light on the experiences of patients and impacted individuals on emotional and health consequences of COVID-19, overdose rates and barriers in safely accessing care during the pandemic. Supported in part by the National Institute on Drug Abuse (NIDA), a part of the National Institutes of Health (NIH).

Authors

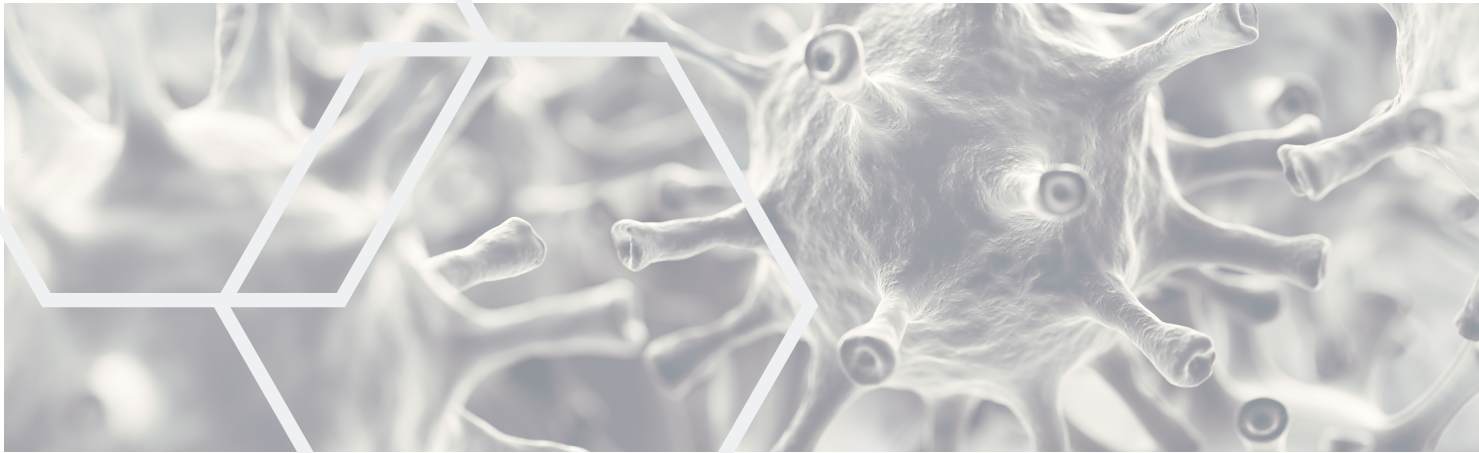
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COVID-19 Survey Overview

The Addiction Policy Forum conducted a pilot study to better understand the impact of COVID-19 on individuals with substance use disorders (SUDs) and to inform subsequent studies. A web-based survey was administered to our network of patients, families and survivors between April 27 and May 8, 2020. The web-based survey was completed by 1,079 SUD patients and impacted individuals whose responses were included in the analyses for this report. An additional 533 individuals partially completed the survey. The research provides insight into the experiences of patients, those in recovery and family members on the emotional and health consequences of COVID-19, including overdose rates and barriers in safely accessing care during the COVID-19 pandemic.

Key Takeaways

- Twenty percent of respondents reported increased substance use since the COVID-19 pandemic began.
- One in three respondents (34%) report changes in treatment or recovery support services due to the COVID-19 pandemic. Fourteen percent reported being unable to access needed services.

34%

report changes in
treatment or recovery
services due to pandemic

- Three percent of respondents reported a non-fatal overdose and 1% reported a fatal overdose since the pandemic began. The South Atlantic region reported the greatest number and percent of overdoses.
- The top emotions reported by respondents are worry (62%), sadness (51%), fear (51%) and loneliness (42%).

4%

report overdoses since the
pandemic began

- Eighty-seven percent of those who report access disruptions (n=266) also report emotional changes since the pandemic began, compared to 72% of those who do not report access disruptions (n=806).
- Forty-eight percent of patients and families reported fear of becoming infected with COVID-19 as a top concern, followed by spreading the virus (46%) and social isolation (40%).

Caveats and Limitations:

- Survey respondents were predominantly white (88%), non-Hispanic (88%), female (66%), over the age of 26 (95%), and more than half had college degrees or higher. Findings should be interpreted within that context and may not represent the broader community of those impacted by SUD.
- This survey was designed to be a rapid assessment of the impact of COVID-19 on the SUD community and to inform additional research. Future studies will include a larger, representative sample to uncover individual, social, cultural, economic, geographic, and other factors that interact with both SUD and COVID-19.

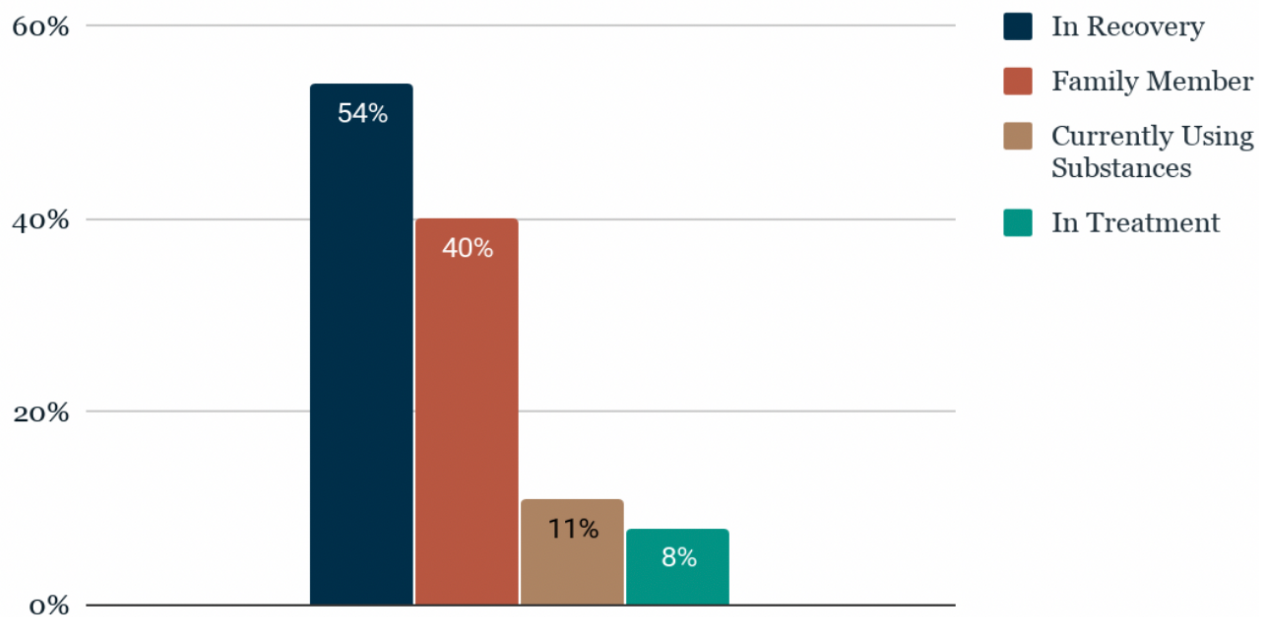
Respondents from a Broad Cross-Section of SUD Impact

Patients and family members wanted to share their experiences.

The survey included a range of U.S. addiction patients who have been diagnosed with a SUD, are in recovery, have an active SUD, as well as family members impacted by addiction. Most respondents selected multiple categories to describe personal and family SUD history.

Fifty-four percent of respondents are in recovery from a SUD, 40% have a first- or second-degree family member with a SUD, 11% of respondents are currently using substances and 8% are receiving treatment. Taken together, 73% of responses represent patient perspectives and 40% represent family members.

Self-Identified Respondent Categories



Note: Respondents could report multiple categories

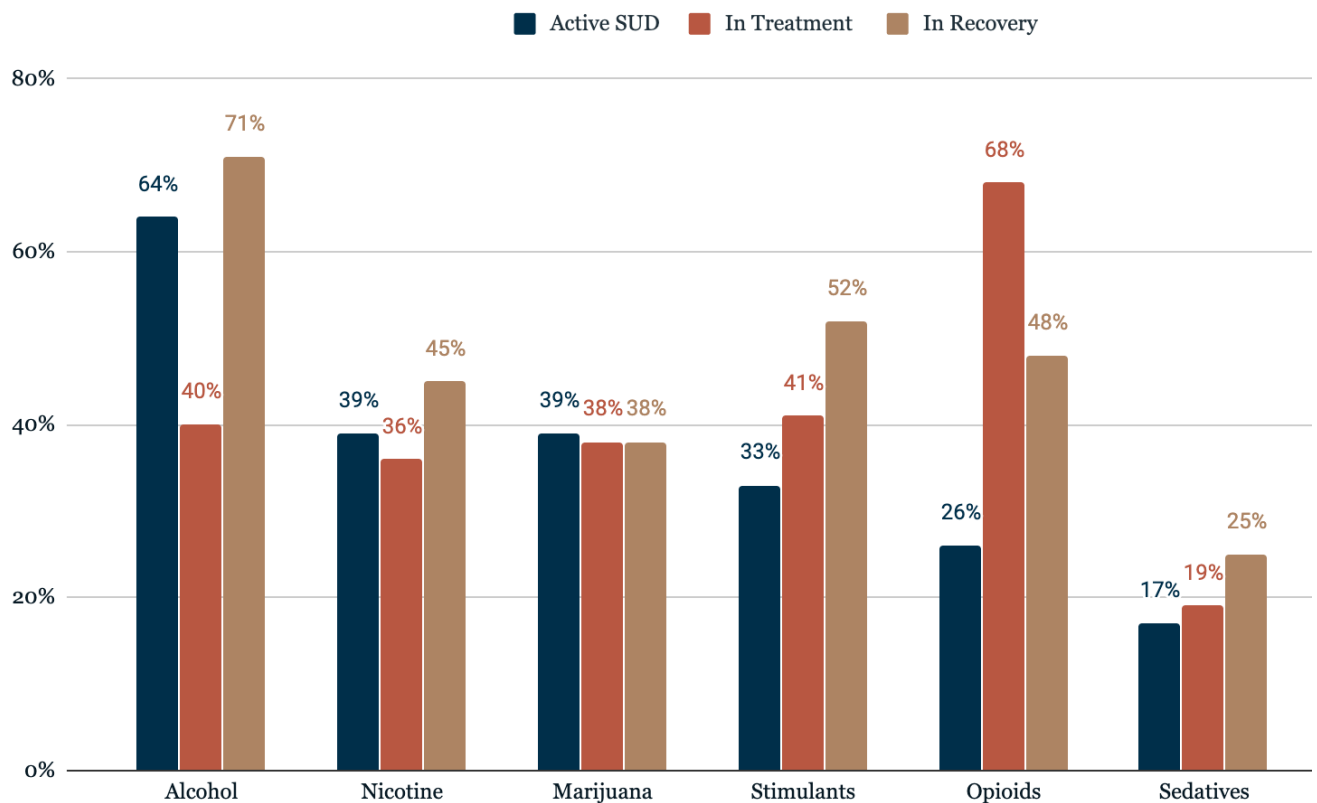
Polydrug Use Top Concern; Alcohol, Opioids and Stimulants Follow

Following broader trends, most people with SUD are impacted by multiple substances.

To more deeply examine substance use trends among people with SUD themselves, these participants were then categorized into one of three groups: active SUD, in treatment, and in recovery. For additional detail, see methodology.

Of respondents with an active SUD (n=117), the most prevalent substance reported was alcohol (64%), followed by marijuana and nicotine both at (39%) and stimulants (33%). Fifty-eight percent reported polydrug use, meaning more than one substance of issue was reported, while 42% reported a single drug of concern.

SUD by Respondent Category



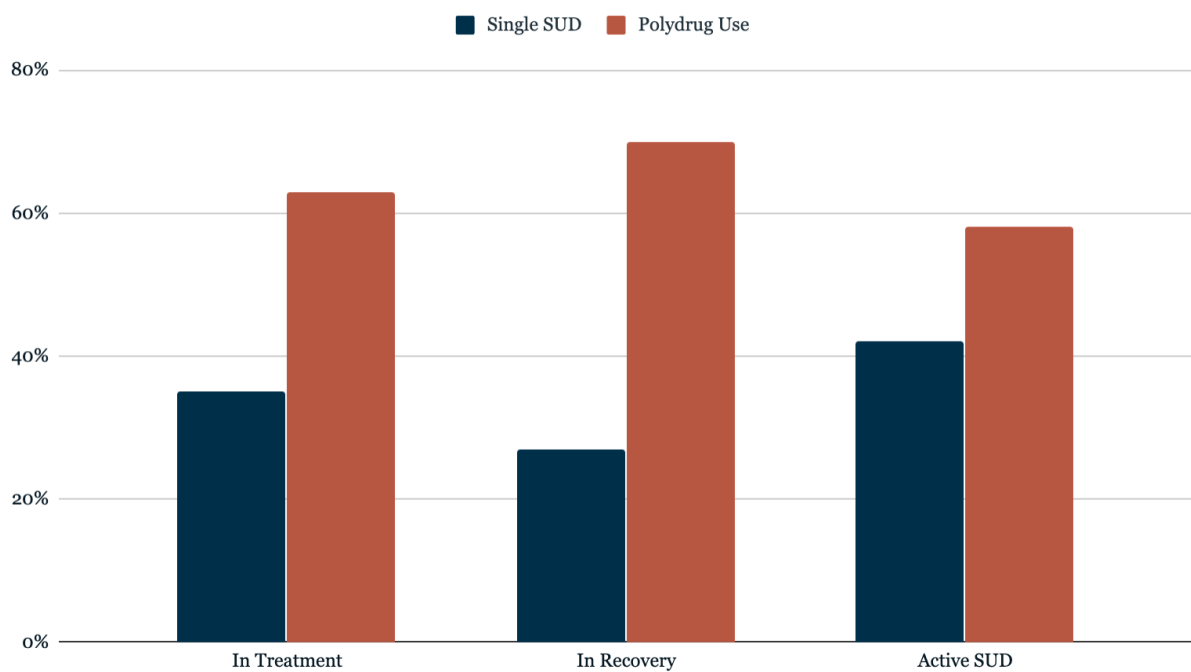
Note: Respondents could report multiple substances

Source: Addiction Policy Forum

Of respondents receiving treatment for a SUD (n=81), 63% reported polydrug use, while 35% reported a single drug of concern. The most prevalent substance reported was opioids (68%), followed by stimulants (41%) and alcohol (40%).

For individuals in recovery (n=568), alcohol was the most prevalent substance reported (71%), followed by stimulants (52%) and opioids (48%). Seventy percent reported polydrug use, while 27% reported a single drug of concern.

Single SUD and Polydrug Use



Source: Addiction Policy Forum

Reduced Access to Treatment and Recovery Services During the Pandemic

Treatment disruptions are common, and support groups are particularly important to patients and families.

One in three respondents (34%) report changes or disruption in treatment or recovery support services due to the COVID-19 pandemic.

- 14% say they were unable to receive their needed services.
- 7% say they are unable to access in-person support groups.
- 2% and 3%, respectively, say they were unable to access syringe or naloxone services specifically.

14%

of respondents report they were unable to receive needed services

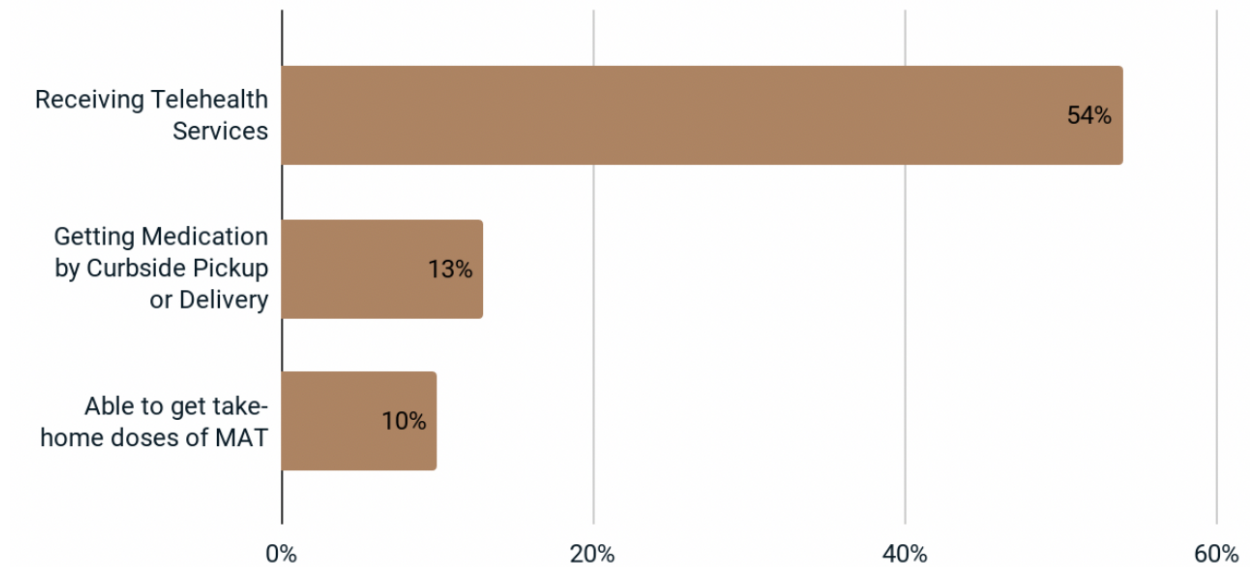
How Treatment is Changing

Virtual transitions, changed medication schedules, and feeling unsupported.

Among patients and families reporting changes in their service delivery, many report accessing modified access points for treatment and recovery services, from telehealth availability to alternate ways of acquiring medication for addiction treatment (MAT).

- 18% report they are receiving services by telephone or online (telehealth),
- 4% report access to medications via curbside pickup or delivery; and
- 3% report ability to access more doses of take-home medication at one time than usual.

Changes in Service Delivery



Source: Addiction Policy Forum

Respondents cited the lack of access to in-person 12-step or support group meetings as a primary concern through write-in responses and additional feedback. Comments on changes to services included: *"The closing of Recovery drop-in, peer-run recovery centers. **No ability to socialize/connect or get peer support.**"* Another respondent commented: *"Meetings have all been reduced to Zoom and it has had an **impact on feeling supported by peers** and getting a good recovery message."* A family member participant added, *"**the inability of attending meetings** in person and meeting a sponsor in person has been **very difficult for my child.**"* Another respondent added: *"Doing **online meetings are not the same** as going to a meeting."*

Note that even among responses to our online survey, 2% of participants reported that they do not have in-home high-speed internet access, which is a challenge for telehealth service access.

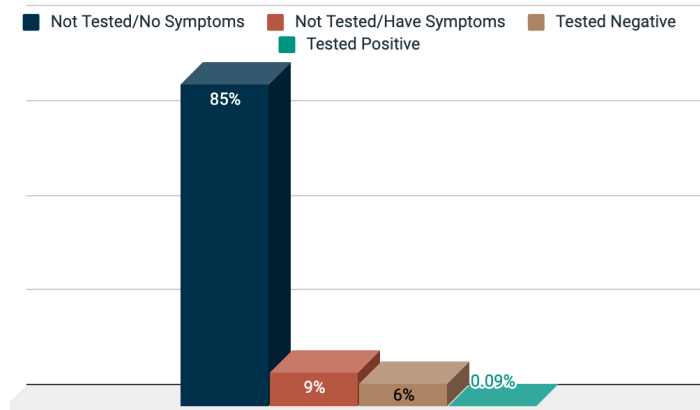
COVID-19 Effects and Concerns

Top concerns are related to getting or spreading COVID, but patients and families are also worried about isolation, job loss and hospitalization.

While only one respondent reported a diagnosis of COVID-19, 9% report symptoms though they never received testing. Fever, cough and flu-like symptoms were the most common symptoms reported.

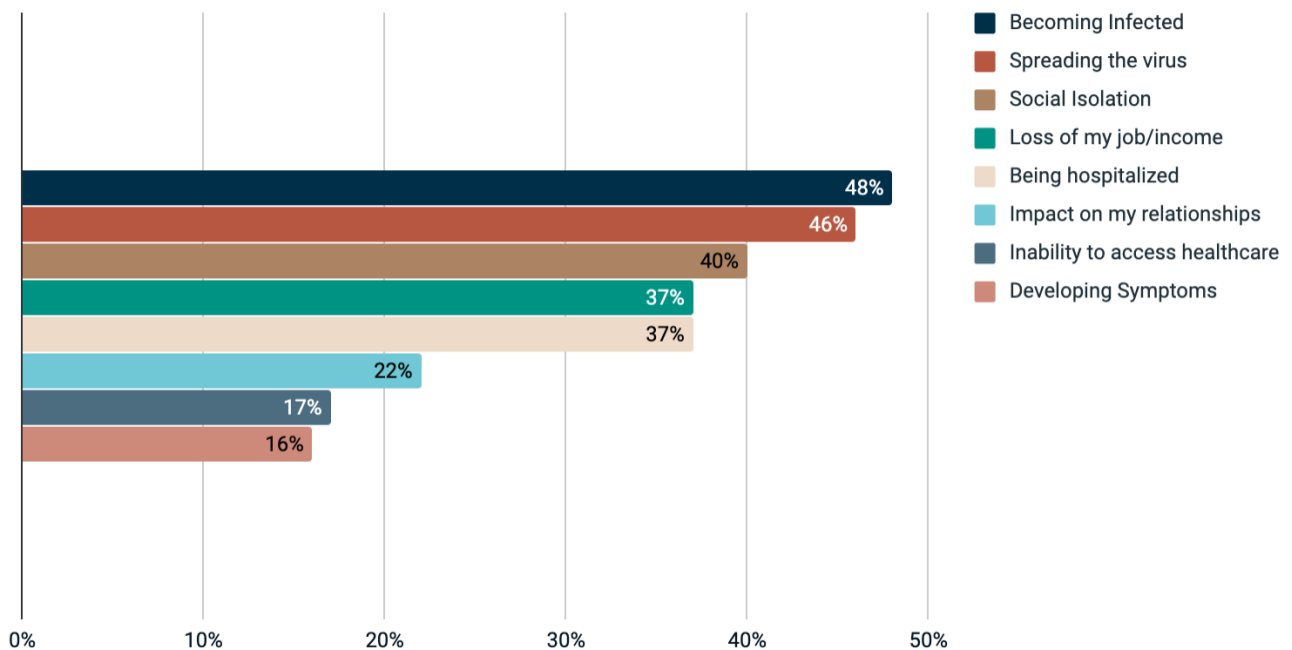
Forty-eight percent of patients and families report fear of becoming infected with COVID-19 as a top concern, followed by spreading the virus (46%) and social isolation (40%).

COVID-19 Testing and Symptoms



Source: Addiction Policy Forum

Concerns About COVID-19 Pandemic



Source: Addiction Policy Forum

Emotional Effects, Substance Use Behaviors and Overdoses

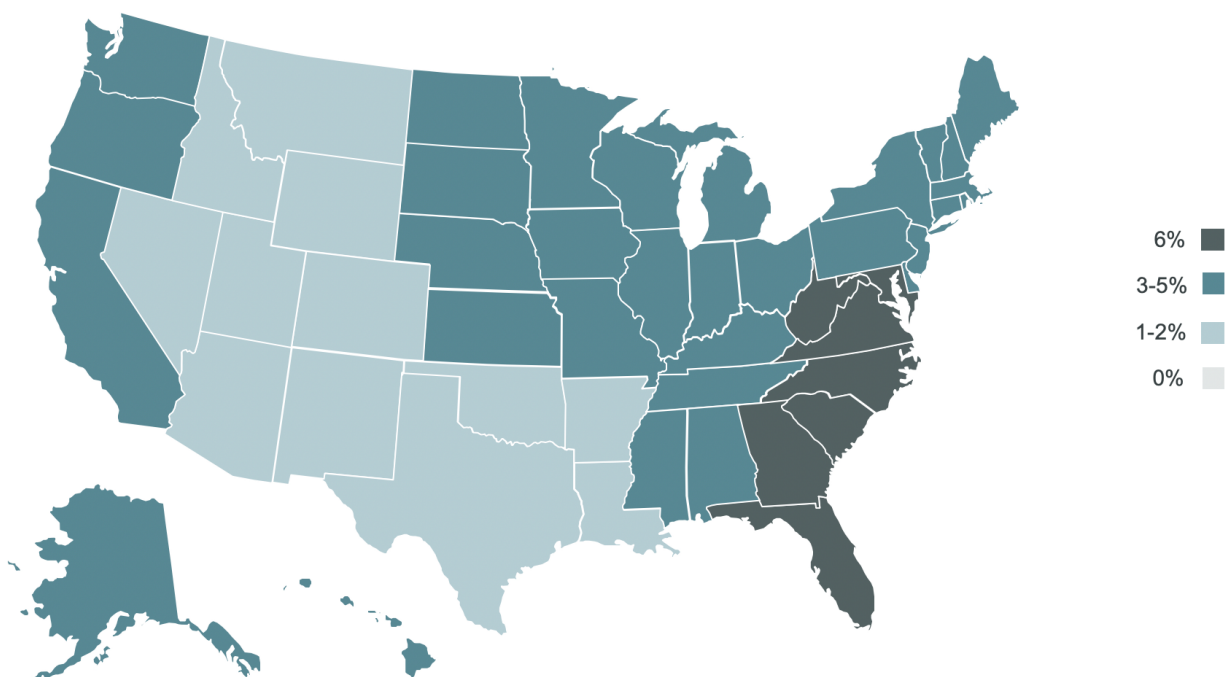
Treatment disruptions exacerbate the emotional stress of the pandemic.

Overall, 74% of respondents said they had noticed changes in their emotions since the pandemic began. The percentage of those who reported emotional changes was higher among those who have had changes in treatment access. Among those who reported changes in treatment access, 87% report emotional changes.

Twenty-four percent of respondents indicate that their/their family member's substance use has *changed* because of COVID-19 -- 20% reported increased use and 4% reported a decrease.

Nationwide 3% of respondents report a non-fatal overdose and 1% report a fatal overdose has occurred since the pandemic began. The South Atlantic region reported the greatest number and percent of overdoses. The region includes Delaware, Maryland, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida and the District of Columbia.

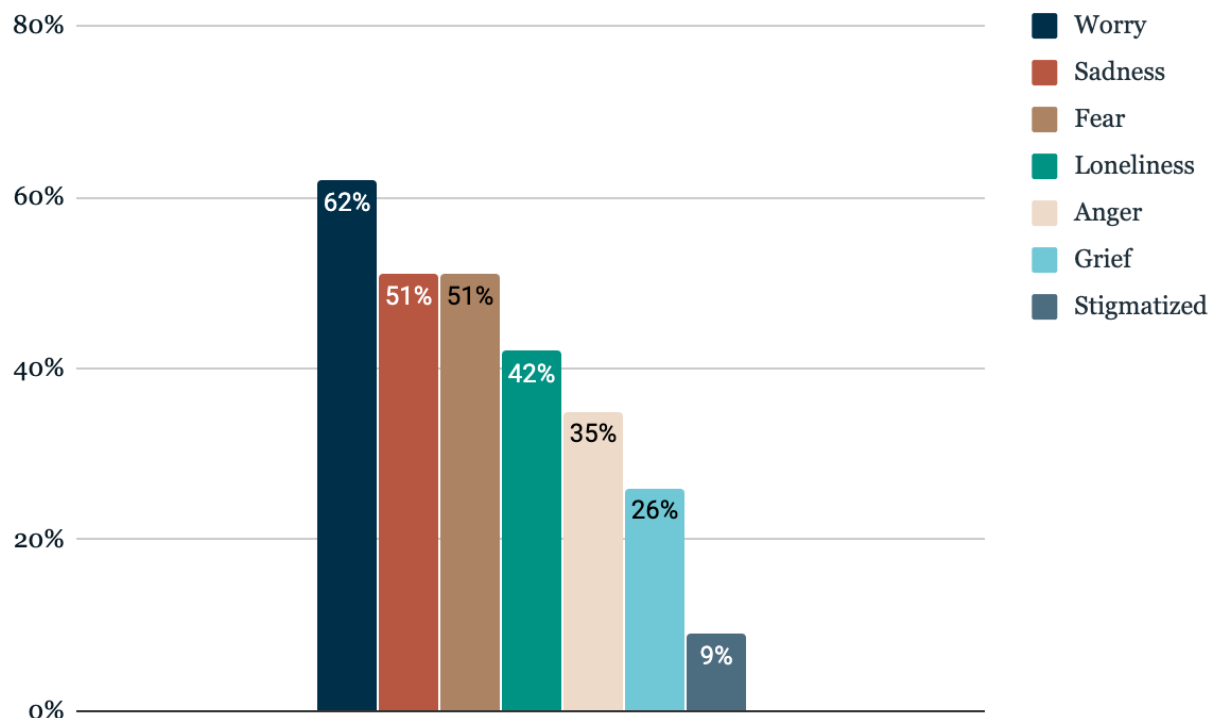
Overdoses by Census Region



The top emotions reported by respondents are worry (62%), sadness (51%), fear (51%) and loneliness (42%).

Although the survey did not include questions about suicide ideation, nine respondents submitted open comments expressing concern about suicidal thoughts and behaviors among family members, friends and community. One respondent reported the suicide death of a parent with SUD.

Emotions that have Changed During the Pandemic



Source: Addiction Policy Forum

Patient Perspectives

Individuals in Recovery or with Active SUD

"Many people are dying from **overdoses due to lack of face to face treatment** being able to get admitted into residential treatment facilities."

"I have been free of illicit drugs for 20 years. During the last month I have felt more at **risk of relapse** than I ever have. I work in the treatment and recovery field and I see that this is having a devastating impact on my community. The people who are most vulnerable and **marginalized** are not being helped. We have made a lot of progress on the opioid "epidemic" I'm worried about what will happen."

"I've **never felt true depression like I have in the past month**. I know alcohol makes it worse, but I feel like I just want to make it through this time by staying comfortably numb."

"I have had **2 friends OD in a week**, people with 2 years cleantime."

"I would say living in a recovery through this time and **not being able to be active in meetings** has been disappointing when they keep liquor stores and weed shops open. This society is so twisted."

"Covid -19 has affected me tremendously in my emotional being from day to day. I am grateful that I'm sober/clean during this time, especially at this time! But saying that, **I have never thought about using/drinking more during this time then before covid-19 began**. I think about it every single day all day."

"I am in recovery and I lost my daughter in 2017 from an overdose. I feel like my **grief was enhanced by this covid19**."

"I've known a few people who have **started using again that had multiple years of recovery**. This has made me **anxious** about my own recovery even though I haven't been tempted to use or planning to use."

Family Perspectives

Individuals with a loved one struggling with addiction, in recovery or lost to addiction

"It has increased my **PTSD and worry** for my son. I fear he has relapsed. He agreed to see doctor. Doctor can only do telehealth. I am filled with anxiety."

"My son was attending meetings faithfully. He hasn't been as open to attending meetings online. He attended one last week. He really likes the social aspect of the meetings. I can see it has affected him because he made friends in recovery. He has not been able to see them and has been **isolated**."

"My spouse does not acknowledge his alcohol dependence and laughs about **drinking more** now that he is unable to work or go anywhere."

"My sibling is in recovery and has been for over a year but, with the increased pressure and **risk** associated with their work and the stress of the situation I have **worried** about a possible return to use."

"My husband (who uses) has not been socially isolating, so I'm **worried** about us getting sick or getting my family sick."

"I worry all of the time that my daughter may become so isolated she may make **decisions not beneficial to her recovery**."

"My parent was doing well in recovery - seeing a therapist, going to AA meetings daily, and getting out and about to stay active. Being stuck inside and **socially isolated resulted in a relapse**. He is hard of hearing so has not been able to utilize telehealth and his therapist's calendar has been booked up."



The Need for More Research

To better understand the impacts of COVID-19 on the broad and diverse community of people impacted by SUD, and to answer the questions patients and families still have, we need more research.

The responses to this initial study indicate overwhelming unmet needs of individuals with active SUDs, those in treatment and recovery, and their families. Future research will need to include a larger, representative sample of individuals impacted by SUD to help us understand the variety of pandemic-related impacts that interact with individual, social, economic, geographic and other factors.

- *How do pre-existing health vulnerabilities and economic disparities among SUD patients impact risk of and care for COVID-19?* Participants are especially worried about becoming infected with and spreading COVID-19. Are those with substance use disorders especially vulnerable to COVID-19, either clinically or socially, given preexisting health and economic disparities? Are SUD patients, who are commonly uninsured, able to access testing and treatment when they have COVID-19 symptoms? If they do pursue care, is the clinical care they receive impacted by the stigma associated with their SUD?
- *What are the effects of sudden changes in treatment, including virtual options, curbside pickup, and an overall reduction in in-person services?* Responses here suggest that changes in treatment are associated with distress, but clinical

research is needed to understand whether these emotional changes come with poor treatment outcomes. As clinicians shift to offering telehealth services, curbside pickup, and extended dosing for medications, what are the effects on patients? Do treatment and recovery disruption fears top COVID infection fears?

- *What are the impacts of COVID-19 on overdoses, at a regional and national level?* These data cannot settle the question of whether overdoses are increasing, or becoming more dangerous, because of COVID-19. However, they suggest a decrease in access to naloxone. Do rates of overdoses, or overdose fatalities, change as drug supply chains shift? Do overdoses become more likely to be fatal as people with SUD report lower access to naloxone? Is there evidence of reluctance among first responders to administer naloxone for fear of COVID transmission?
- *How does COVID-19 impact the mental health needs of SUD patients?* Respondents who expressed emotional changes related to the pandemic were worried, sad, afraid and lonely. This study was not designed to assess the prevalence of specific mental health crises, but future research should investigate whether these emotional changes coincide with broader mental health challenges. Are those with SUD particularly prone to mental health crises during this period? Are there any services that can be deployed to meet the mental health needs of SUD patients and their caregivers?
- *What are the effects of isolation and overall stress on long-term recovery?* After acquiring or spreading COVID-19, respondents' top concerns were social isolation and economic turmoil. Overall, respondents indicated that the sudden changes associated with COVID-19 had challenged even those in long-term recovery. How risky is this environment for those in long-term recovery? How can we help those in recovery with these worries?

Methodology

Data provided by patients and families as part of this project allow for a greater understanding of their experiences and opinions on addiction-related issues and give voice to patients and families. Due to the urgent need to understand the impact of COVID-19 on individuals with a SUD and their families, this survey was deployed through an anonymous survey and distributed via email to the Addiction Policy Forum national network and promoted through the organization's social media accounts to recruit respondents.

All research protocols, instruments and communication materials were reviewed by the IntegReview Institutional Review Board.

The survey population comprises individuals who meet the following criteria:

- Individuals with an active SUD, in recovery from a SUD, receiving treatment for a SUD or a family member impacted by addiction; and
- Over the age of 18.

The data were collected between April 27, 2020 and May 8, 2020. A total of 1,079 participants responded to the survey. Demographics are given in the following table.

| Demographics | | |
|--------------|---|------|
| Race | White | 88% |
| | Black or African America | 4.4% |
| | American Indian/Alaskan Native | 1.7% |
| | Asian | 1.2% |
| | Native Hawaiian or other Pacific Islander | 0.2% |
| | Other | 5% |
| Ethnicity | Non-Hispanic | 88% |
| Gender | Female | 66% |
| Age | 18-25 | 4.3% |
| | 26-40 | 33% |
| | 41-60 | 45% |
| | 61 or older | 17% |
| Education | Less than high school | 1.1% |
| | High school graduate (includes equivalency) | 12% |
| | Some college, no degree | 24% |
| | Associate's Degree | 11% |
| | Bachelor's Degree | 27% |
| | Graduate of professional degree | 25% |

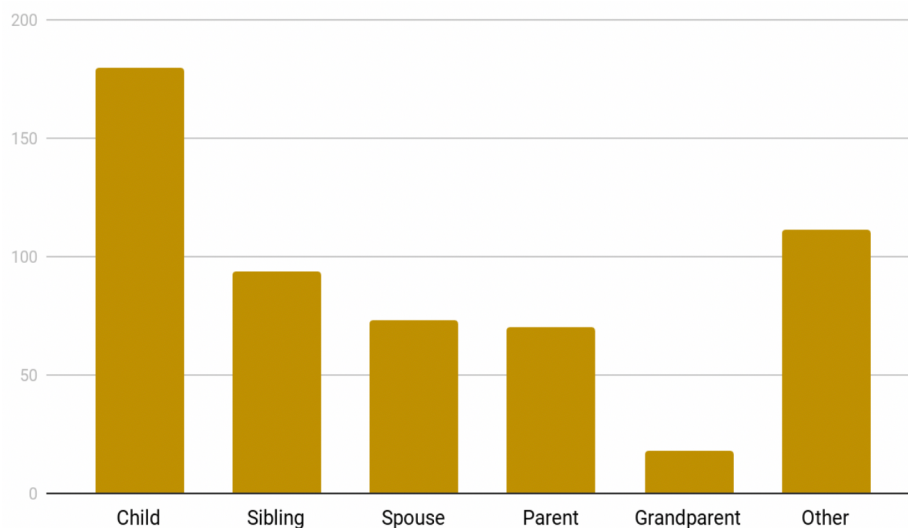
Categorization of SUD Impact

Participants were categorized into a single SUD impact category to better characterize trends among patients with an active SUD, those in treatment, and those in recovery. The "Active SUD" group includes only those who endorsed "currently using substances". Remaining participants who endorsed "receiving treatment for substance use disorder" were categorized as "In Treatment". Finally, remaining participants who endorsed "in recovery from a substance use disorder" were categorized as "In Recovery."

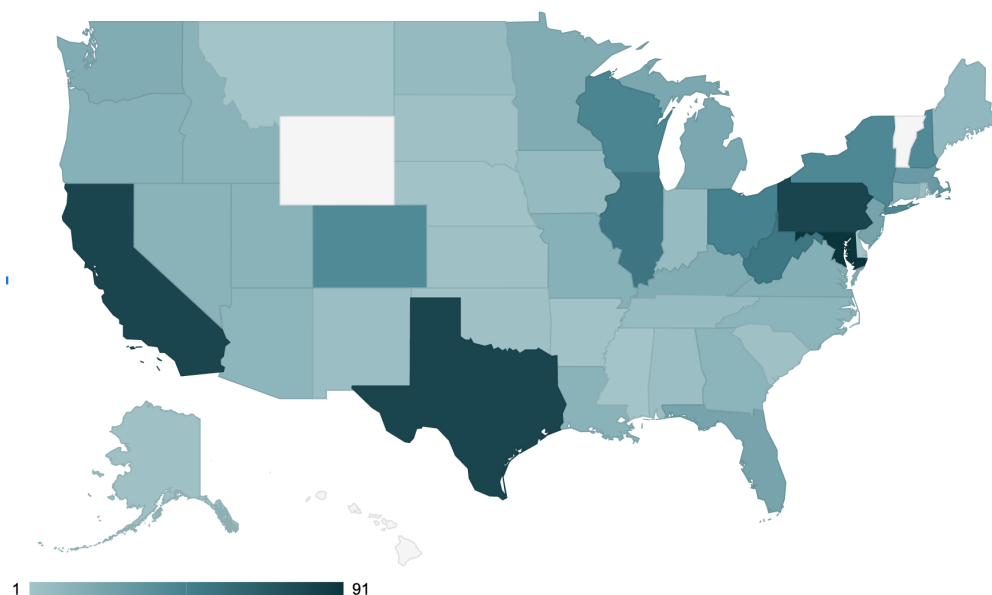
Family Members include Parents, Siblings, Spouses

Of the 411 family members surveyed, 44% have a child with a SUD, 23% report a sibling with SUD, and 18% report a spouse with SUD.

Family Member



Respondents by State



Acknowledgments

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This white paper was reviewed by the Addiction Policy Forum Scientific Advisory Board.

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About the Addiction Policy Forum

The vision at the Addiction Policy Forum is to eliminate addiction as a major health problem by translating the science of addiction and bringing all stakeholders to the table. The organization works to elevate awareness around substance use disorders and help patients and families in crisis. Founded in 2015, Addiction Policy Forum empowers patients and families to bring innovative responses to their communities and end stigma through science and learning.

