ADDICTION POLICY FORUM

Patient

JOURNEY MAP

Substance Use Disorder Treatment and Recovery Experiences

June 2022

About

The Addiction Policy Forum was named one of the winners of the National Institute on Drug Abuse "Mapping Patient Journeys in Drug Addiction Treatment Challenge"; funds from this prize were used to support the development of this report.

The Patient Journey Map highlight the experiences of a diverse set of patients through treatment and recovery from substance use disorders (SUD). The map underscores the pain points, challenges and bright spots encountered across seven distinct phases: 1) Onset and Progression; 2) Trigger Events: 3) Getting Help; 4) Care Begins; 5) Treatment and Recovery; 6) Lifestyle Changes; and 7) Ongoing Support.

Addiction Policy Forum aims 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.

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CONTENTS

I love being able to have a life that I couldn't have dreamed of over seven and a half years ago. I love the freedom. I love the serenity the peace that I have. I love that I have skills today that I can use when I'm having a really good day or a really bad day. I have a sense of purpose and meaning that largely accounts from my own spiritual beliefs and practices that I never had before. The obsession to want to use has left me.

-Patient Journey Map Participant

Introduction

About the Patient Journey Map

Addiction Policy Forum's (APF) Patient Journey Map was developed through the input of patients in treatment and recovery from substance use disorder (SUD). The map underscores the obstacles and positive points patients encounter across seven distinct phases, from treatment to finding long-term, stable recovery.

The qualitative study included 60 Life Course History interviews of individuals in recovery from substance use disorders across 22 states and Canada.

Fig. 1. Phases of Patient Experience

Phase	Details
Onset and Progression	• Age of onset, specific risk factors for the development of a SUD, as well as problems and health consequences of active addiction
Trigger Events	• Events that contribute to the patient to assess their own symptoms and recognize the need for treatment or other support.
Finding Help	• Patient conducts research and reaches out to identify resources, initial outreach to service provider
Care Begins	• Connection to treatment or other services; assessment process if applicable
Treatment and Recovery	• Services and resources accessed by the patient, both within the healthcare system and outside
Lifestyle Changes	• Changes and modifications to daily life and routines to support and maintain recovery and promote long-term wellbeing
Ongoing Support	• The supports and interventions that patients utilize for long-term recovery

Participants Overview

Of the 60 participants, 55% identify as female (n=33) and 45% male (n=27). The race and ethnicity breakdown of participants is as follows: 60% non-Hispanic White; 18% Hispanic/LatinX; 13% Black or African American; 5% Native American/Alaskan Native; 3% Asian or Asian-American; and 7% identify as more than one race. Participants were from 22 U.S. states and Canada.

The study included individuals in recovery from a SUD. Seventy-two percent report a single, primary SUD, 28% reported a polysubstance use disorder, and 98% report using multiple substances during active addiction. The breakdown of types of SUD is as follows: 19 participants reported an alcohol use disorder, 17 a polysubstance use disorder, 13 an opioid use disorder, 9 a stimulant use disorder, and 2 a cannabis use disorder.

Study Design

Addiction Policy Forum collected the data between August 12th and December 12th, 2021. All research protocols, instruments, and communication materials were reviewed and approved by an independent institutional review board. The interviews were conducted by CITI-trained APF staff who are in recovery from a substance use disorder. Sixty interviews were conducted with variance in geography, race/ethnicity, gender, socioeconomic background and SUD type. The project utilized a life course history structure, followed by a rapid qualitative inquiry to analyze the data.

Life Course History Interviews

As a concept, life course theory is defined as "a sequence of socially defined events and roles that the individual enacts over time." [1] Life Course History interviews are a person-centered research method that requires "respondents to provide a subjective account of their life over a certain period of time, described in their own words, across their own personal timelines." [2] Life Course History one-on-one interviews empower patients with lived experience to tell their unique stories in a semi-structured interview process with time to reflect and describe their journeys.

1 Giele, J. Z., & Elder, G. H., Jr. (Eds.). (1998). Methods of life course research: Qualitative and quantitative approaches. Sage Publications, Inc.

2 Davies, J., Singh, C., Tebboth, M., Spear, D., Mensah, A., & Ansah, P. (n.d.). Conducting Life History Interviews: A How to Guide.

Fig. 2. Participant Demographics and Characteristics

Demographics	
Total Participants	60
Sex	
Female	55%
Male	45%
Age	
18 - 29	15%
30 - 44	40%
45 - 59	35%
60 and Older	10%
Race/Ethnicity	
American Indian/Alaskan Native	3%
Black/African American	10%
Hispanic/Latino	17%
Asian	3%
White/Non-Hispanic	60%
One or more race	7%
Education	
Some High School or less	5%
Completed High School or GED	18%
Some College (no degree)	38%
College Degree (AA, BA, etc)	27%
Graduate Degree (MA, JD, PhD)	12%
Polysubstance Use Disorder	
Single Substance Use Disorder	72%
Polysubstance Use Disorder	28%
Type of Substance Use Disorder	
Alcohol use disorder	32%
Polysubstance use disorder	28%
Opioid use disorder	22%
Stimulant use disorder	15%
Marijuana use disorder	3%

This qualitative approach to data collection allowed APF to build a comprehensive and accessible patient journey map that illustrates how complex interactions over the course of an individual's life contribute to the onset, progression, and treatment of a SUD and the elements of long-term recovery.

Interviews included questions related to substance use; trauma and adverse childhood experiences; treatment episodes; facilitators and barriers to seeking and pursuing treatment and recovery; and other information related to lived experience with addiction and recovery, building upon existing validated instruments as well as open questions and conversation to allow for engagement.

Instruments used include the Addiction Severity Index (ASI), the Inventory of Drug Use Consequences (InDUC), Adverse Childhood Experiences Screening, and the Global Appraisal of Individual Needs (GAIN). Each interview began by securing consent from the participant. The audio recording and a transcript of each interview were used for text analysis and coding of individual responses.

Rapid Qualitative Inquiry

The Rapid Qualitative Inquiry (RQI) framework was used to quickly develop a preliminary understanding of the often complicated and varied experiences of accessing treatment and recovery for substance use disorder.

According to Dr. James Beebe, the RQI allowed for a team-based approach to quickly develop an insider's perspective to a specific situation.[3] A small multidisciplinary team of four staff conducted the RQI. The multi-discipline strategy ensured that different perspectives were represented on the team and that individual biases were checked, a key component of rapid qualitative inquiry and the success of the patient journey mapping process.

3 Beebe J. Rapid Qualitative Inquiry : a Field Guide to Team-Based Assessment / James Beebe. 2nd ed. Rowman & Littlefield; 2014.

ADDICTION POLICY FORUM

Patient Journey Map

The Addiction Policy Forum Patient Journey Map represents a common set of moments that individuals in treatment and recovery from a substance use disorder experience. While this map does not represent what happens to every individual who engages in treatment for addiction and recovery support, it highlights common elements, bright spots, and pain points in accessing care and finding and maintaining long-term recovery.

Quotes from patients are included to illustrate the salience of the moment. Common threads and insights are also provided, which can guide practitioners and leaders in the improvement of care and patient outcomes for individuals with a substance use disorder.

Each phase highlights the bright spots and pain points derived from actual patient feedback, along with common threads and insights relevant to the patient experience.

Onset & Progression

Average Initiation of Substance Use is 14 years old

The earliest age of first use reported was 5 years old; the latest was 19.

78% Report Family History of SUD

85% report a family history of substance use disorders. Patients report an average of 2 previous generations of SUD history.

Polysubstance Use Prevalent

Nearly 1 out of 4 respondents report a primary polysubstance use disorder while 98% report using multiple substances during active addiction, with an average of 6 different substances used.

Childhood Trauma Significant Risk Factor

90% experienced adverse childhood events with an average ACEs score of 4.3, while 47% of patients reporting an ACEs score of 5 or higher. Over 83% experienced household dysfunction, 78% experienced abuse, and 55% suffered from neglect.

Hospitalization

78% of patients were hospitalized due to their SUD, most commonly for injuries, infections, overdose, suicide attempt/self-harm, and car accidents.

Justice Involvement

70% of patients report justice involvement. 63% experienced incarceration and 35% participated in a diversion program, such as drug court.

Overdose

17% of patients have experienced an overdose.

Suicide

23% of patients report suicide attempts or suicidal ideation.

Problems Caused by SUD

- Damaged Relationships
- Financial Problems
- Personality Changed
- Homelessness

Trigger Events

Patients report multiple trigger events with the most prevalent reason for engaging in treatment being tired/wanting change (87%), followed by health reasons (35%), pressure from loved ones (23%), parenting/custody concerns (22%), and pressure from the criminal justice system (20%).

Tired/ Want Change

"I just was desperate I didn't want to use anything anymore, I was tired."

- Children & Family

  "I didn't want to be separated from my daughter again and risk that being the cycle of her seeing me in and out of prison all throughout her life."

- Isolation

  "I was in jail, I was away from my kids, it was scary."

Health Reasons/ Injury

"I was doing like over three grams a day by myself and I was still sick all the time in withdrawal, no matter how much I did."

- Relief

  "It was just like relief -- I'm finally going to go do this."

- Shame

  "Just so much shame. The word doesn't even encapsulate what that feels like you know. I had utter hatred for myself."

Pressure from Loved Ones

"[My Dad's friend] told me you don't always have to live like this and it kind of planted the seed, that's all he said to me."

- Hope for Change

  "Knowing that I was turning a new leaf and knowing that I was going from a very negative outlook and existence to looking forward to a very positive one."

- Lost Relationships

  "I lost all my family, I had nothing to my name anymore, I finally realized the people that I was with did not care about me in the least bit. Yeah, I had nothing."

Parenting/ Custody

"I wanted to reunify with my children, and I was sick and tired of being sick and tired."

- Encouragement from Others

  "My pastor called. When I told him I was going to get help and he was like I'm glad you did that. But that was the only bright spot."

- Fear

  "Not knowing if I could do it, or like what my life would be like, if I entered recovery."

On average, patient shared three separate trigger events that contributed to engaging in treatment, a cluster of events that constitute the Aha moment. The events weren't necessarily close in timing, but represented meaningful moments for the patient.

Getting Help

Poor treatment access was a common experience among participants who experienced systemic barriers to addiction care, including high levels of stigma (32%); the complexity of navigating the substance use disorders care system (25%); wait times (20%); the high costs of treatment (8%); red tape payer policies such as fail first and prior authorization (7%); and transportation difficulties (5%).

Looked for Treatment Directly

"I researched the methadone clinic and decided that that was probably what I needed to do."

- Friends/Family in Recovery

  "Well, my brother was in recovery, so I at least knew someone and didn't completely feel alone at that point."

- Waiting for Access

  "The wait, the wait time is long. I was in withdrawal, so the desire to leave and go, you know get well, was really strong."

Talked to a Loved One/Friend

"I reached out to my probation officer and said I need help and he put me into a residential treatment center."

- Not Alone

  "I was no longer alone, because I was in a group setting, so the loneliness dissipated."

- Withdrawal Symptoms

  "It was very difficult, the withdrawing and not being able to use because I couldn't [take a] hit."

Looked for Support Group

"I went to a ton of meetings, I went to three meetings a day, or more, just completely immersed myself in the recovery community".

- Smooth Transition

  "After the assessment I didn't have to wait a very long time. I think there was a sense of relief if that makes sense."

- Not Finding Help

  "So in my experience, I was not able to get help when I needed it or when I asked for it, begged for it."

Talked to Mental Health Professional

"I went to see the therapist and they put me in the hospital."

- Finding a Community

  "I started realizing that there's a lot of people in my community who are sober."

- Navigating Insurance

  "I found it to be difficult navigating the insurance. And there wasn't a lot of choices, there wasn't enough beds."

The accessing help phase is often identified by patients as extremely painful, disorganized and difficult. Previous treatment and recovery experiences, along with recommendations from friends, family and a person's network frequently form the basis for the treatment pathway selected.

Care Begins

Direct engagement with a specialized treatment provider was the most often utilized first point of contact to find help (37%), followed by hospital or emergency room (20%), doctors (15%), mental health provider/counselor (7%), and criminal justice agencies (3%).

Treatment Facility First Point of Contact

Previous experiences and treatment episodes guide the first contact and research conducted by patients.

Co-Occurring Disorders Prevalent

67% have a co-occurring mental health disorder. Depression, anxiety disorder, and bipolar disorder are the most common diagnoses.

Trauma Experienced During Active Addiction

Trauma often experienced during active addiction, including physical violence and sexual assault.

Friendly, Engaging Staff

"So there were people along the way that were just kind, and sometimes that was all it took."

Employment/ Housing

"I mean, I had a roof over my head. And I had a part time job. And I had the support of my family."

Peers/Recovery Coaches

"I think, for me, what kind of helped was the gentleman that I met at that treatment Center door...and he shared his experience with me. I identified with him."

Difficulty Repeating History

"The reliving my bottom, having to constantly re-discuss it ...was probably the roughest point of the assessments."

Isolation

"I still was living in my car. And I really thought that by signing myself into treatment that [my parents] would let me come home and that didn't happen."

Feeling Stigmatized

"Well, I definitely felt stigma, I definitely felt [the assessment] was long, it was way too many questions, it was like being interrogated. I just didn't have the mental capacity to endure that at that time because I felt so defeated and beat up and ashamed and guilty."

Repetitive assessments and interviews during the care phase were a consistent difficulty among patients with reports of feeling triggered and interrogated. Patients also questioned the utility of multiple interviews and the coordination of providers.

Treatment & Recovery

On average, patients utilized four different services for treatment and recovery support, not a single treatment or intervention. Services accessed were support groups (88%), counseling/mental health treatment (57%), intensive outpatient treatment programs (52%), followed by residential programs (37%), aftercare programs (30%), medications for addiction treatment (28%), sober living (22%), and faith-based programs (12%).

Support Groups

"Another bright spot was the camaraderie of the program, that was really amazing to me, I was so shocked to see all the people in there, I never had any idea."

Counseling/ Mental Health

"It took someone like that therapist that never gave up on me, that kept working with me... to reel me back into realities."

Intensive Outpatient Program

"Intensive outpatient... you really learn about the disease. You see a lot of people that are struggling."

Medications for Addiction Treatment

"They got me into the methadone clinic. So then, I had a counselor at the methadone clinic, my case manager, and my recovery coach."

Aftercare Program

"Our aftercare program is two years, so you get to know people...it provided a sense of community or a support system."

Positive Social Connections

"The social aspect of it because your first couple of years of recovery can be lonely because everyone you know you had to cut out of your life."

Helpful Clinicians

"The counselors call and check on you. The doctor calls and checks on you, even though it's not as often, but yearly he calls to see how you're doing "

New Tools and Skills

"You just learn how to deal with it, the tools that can help you to stay sober."

Learning about the Disease

"It was amazing... You realize you're not alone and you realize that it's, it really is a disease, and that you don't have to do it alone."

Peer/Recovery Coach

"My counselor for sure at treatment, she was actually in recovery herself and she really helped me."

Hard Work/ Difficulty

"It was hard and a lot of work, I mean just the honesty that's required and being honest with myself. I had a problem, but really confronting it doing something about it was what's difficult."

Managing Shame/Self Stigma

"Facing the past, walking through the things... overcoming my identity and how I saw myself and pushing through those things were very painful, it still is every day."

Cutting out Friends/Old Network

"The most painful thing in the beginning, was that I lost people I thought were very close to me and really cared about me. So the painfulness was the realization that drugs are what bound me to a lot of people."

Transportation Challenges

"Riding the bus- I had to take two buses to get there. Sometimes, it was a long day to go to work and then go to treatment and sometimes I was super tired."

Unhelpful Home/Work Environment

"I was in intensive outpatient so it was difficult to be going home or working in an environment where you know, drugs and alcohol were present, you know. So that was challenging, just feeling triggered."

Patients report that previous treatment episodes provided a foundation for treatment and recovery success. Rather than viewing previous episodes as failures, the skills and tools learned accumulated over time. Patient feedback also shows the need for layered interventions across three critical domains: 1) biological, or physical health, 2) psychological, and 3) social.

Lifestyle Changes

Common lifestyle modifications include avoidance of high-risk people, places, and things (42%), changing friends (40%), becoming honest open minded and accountable (25%), self-care such as exercise, nutrition, and sleep (23%), and developing a consistent routine (13%).

Avoiding Risky People, Places, and Things

"Well I moved, out of state, changed my people, places and things, changed routine and old habits, changed things that I did in my spare time."

New Friends

"I had to change the people that I associated with and talk to in my life, I literally had to move away from my home to get sober."

Honesty and Accountability

"I had to be honest with myself and my family about my addiction, because I kept that a secret for a long time. I had to let them in."

Selfcare: Exercise, Nutrition, Sleep

"I started changing my health. I started working out more often and eating better. Just kind of taking care of myself."

Routine/ Management Plan

"Finding some kind of routine, that was hard. "

Ongoing Support

On average patients utilize three services for ongoing support. The most common services were support groups (67%), family and friends (55%), volunteer and service work (38%), and mental health/counseling (22%).

Support Groups

"I actually enjoy going to my meetings now, they're a part of my day, I go to meetings every day,"

Volunteering & Community Service

"I go every month back to the homeless shelter. That's one of my biggest joys... getting to share my inspiration with other people."

Mental Health/ Counseling

"So my therapist is huge in my recovery."

Friendships/ Support Network

"Sense of belonging, getting to know a good group of people or community."

Feeling Happy Again

"Finding joy and the excitement to know that I do have a purpose and the possibilities are infinite."

Being Present in Life Again

"It was appreciating things that I didn't appreciate for a long time, things like being outside and the nice weather and hearing the birds singing..."

Reunited with Children/Family

"Just being clean again, having goals again, being around people that I loved and that loved me was really healing. Just being clean, just delicious, it's wonderful."

Physically Healthier

"I feel like the changes that I made were just kind of self-care as far as like going to therapy...eating healthy, doing exercise, you know, taking care of myself talking to a sponsor, doing step work."

Having a Full Life

"I have full custody of my daughter...I bought a house, I'm gainfully employed, I can drive a vehicle legally....friends, family."

Feeling of Accomplishment

"This feeling of worth and a feeling of accomplishment for what I've done...it makes you feel good about yourself."

Healthy Relationships

"Restoration with my oldest daughter, just closer relationship with my dad and youngest daughter, just an overall feeling of relief and health and gratitude."

Difficulty Making Amends

"Dealing with the consequences of things that I did in my addiction and cleaning up the mess that I made. The trust within my house- my family didn't trust me at all."

Triggers: People, Places & Things

"Knowing people, places and things were a huge part of my recovery, as well as knowing that if I wanted to be in recovery and stay in recovery, I had to cut a lot of people out of my life and make better choices."

MAT Stigma

"I guess stigma from other people for being on a MAT. I went to my family doctor and they wouldn't even entertain anything else other than getting off the methadone."

Trouble Sleeping

"I couldn't sleep anymore, I was so uncomfortable. I remember just kicking around in my bed for hours and hours and hours, and that was really painful."

Sadness/ Depression

"Man I dealt with a lot of mental health stuff...like severe depression and suicidal thoughts and stuff like that. It wasn't pleasant at all."

Health Consequences

"I don't want to be a heart patient, I don't want to be limited on anything. But those are the choices I made in my addiction."

COVID

"Challenges include obviously the COVID thing. I don't want to go to meetings in person, because the people that are in person don't seem to care about COVID."

Limited Access to Services

"In this rural area I'm finding support groups are very limited and if you're a multiple pathway person it's even more limited."

Patients share that the things encountered every day play a critical role in supporting or hampering recovery. Building a positive, supportive social network is a dominant feature of successful recovery, along with avoiding individuals, places and other triggers that present memory and physical cues to resuming substance use (i.e. using friends, bars, parties, concerts, boredom.) The exact constellation of triggers is unique to each patient.

Patients sustain ongoing support specific to their needs for years or even decades. Family/friends, service to others and support group attendance are the most significant components identified by patients.

1 Onset and Progression

Onset is the age at which an individual develops or first experiences a condition or symptoms of a disease or disorder. This section of the Journey Map explains the experiences of onset, specific risk factors for the development of a SUD, as well as health consequences and criminal justice involvement of patients.

Average age of initiation is 14 years old

The average age of first substance use was 14, with the earliest initiation at five years old and the oldest at 19 years old. Patient SUDs include opioid, alcohol, stimulant, marijuana, sedative, and polysubstance use disorder. Nearly one out of four respondents report a primary polysubstance use disorder and 98% report using multiple substances during active addiction.

1 out of 4 patients struggle with polysubstance use disorder

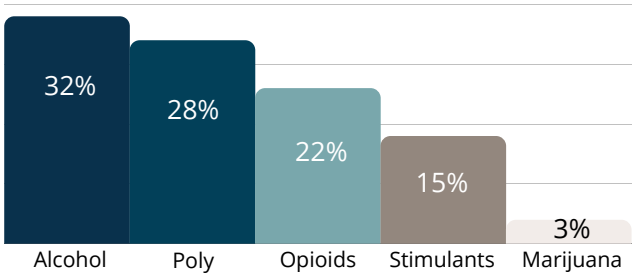
One out of four respondents report a primary polysubstance use disorder, while 98% report using multiple substances during active addiction.

> *"I wouldn't say that one substance brought me to my knees in my addiction. I had my preferences of what I wanted to use, but I would take whatever I could get. I was addicted to feeling different, forgetting the hurt and trauma, and escaping my reality."*

SUD types range from alcohol, opioids, stimulants to polysubstance use disorder

Participants identify a spectrum of SUD types, including alcohol use disorder (32%), polysubstance use disorder (28%), opioid use disorder (22%), stimulant use disorder, which include cocaine and methamphetamine use disorder (15%), and marijuana use disorder (3%).

Fig. 3. Respondents by Primary SUD Type



For participants with a polysubstance use disorder, 35% reported opioid/stimulant use disorder; 24% alcohol/stimulants; 12% alcohol /opioids; 12% alcohol/marijuana/stimulants; 6% alcohol/sedatives; and 6% marijuana/sedatives.

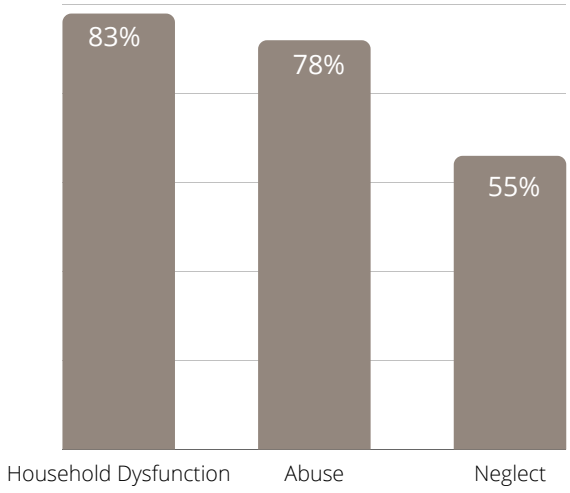
85% of patients report a family history of SUD

Eighty-five percent of the respondents reported a family history of addiction, with an average of two previous generations with SUD history.

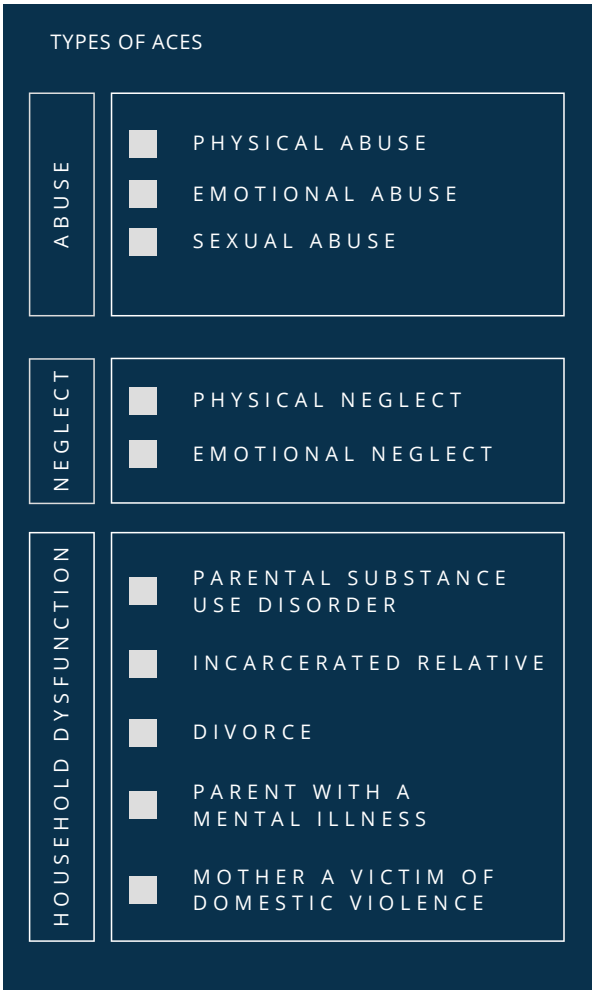
Frequent childhood trauma

Of the study panel, 90% had at least one adverse childhood event. Of those with childhood traumatic events, the average ACEs score was 4.3, with 47% of patients reporting an ACEs score of 5 or higher. Over 83% experienced household dysfunction, 78% experienced abuse, and 55% suffered from neglect.

Fig 4. Types of adverse childhood events participants experienced



Adverse Childhood Experiences (ACEs) are traumatic events that occur between the ages of 0-17.



There are many different kinds of ACEs, including losing a parent, neglect, sexual, physical, or emotional abuse, witnessing a parent being abused, mental illness in the family, and parental SUD. The more ACEs a child has, the more likely he or she is to experience problems later on in life. There are ten types of childhood trauma measured in the ACEs instrument that fall into three categories: abuse, neglect, and household dysfunction.

90% of patients experienced household dysfunction, child abuse, neglect

The most common types of household dysfunction experienced were addiction in the household (62%), mental illness or suicide in the household (55%), parental divorce (55%), an incarcerated parent (22%), and domestic violence (17%). Types of abuse experienced were verbal abuse (58%), physical abuse (48%), and sexual abuse (40%).

Fig 5. Types of household dysfunction and abuse experienced by patients

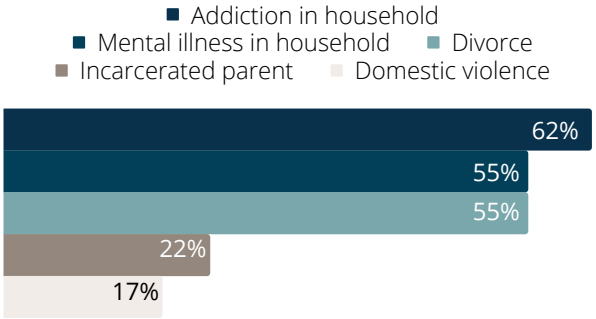
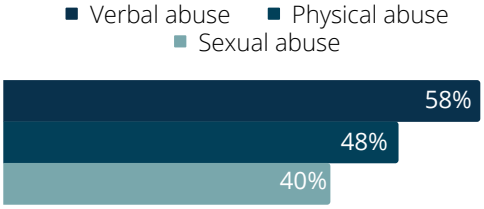


Fig 6. Types of abuse experienced by patients



3 out of 4 hospitalized due to their addiction

Three out of four patients were hospitalized due to their SUD, most commonly for injuries, infections, overdose, suicide attempt or self-harm, and car accidents. 17% of patients experienced an overdose and 23% of patients report suicide attempts or suicidal ideation.

Fig 7. Percentage of participants who were hospitalized as a result of their SUD

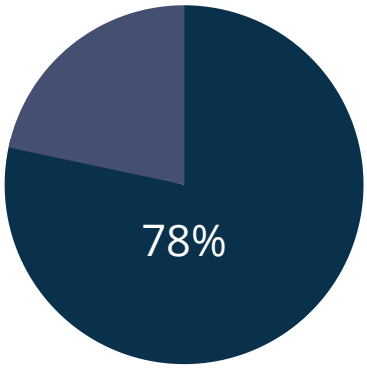
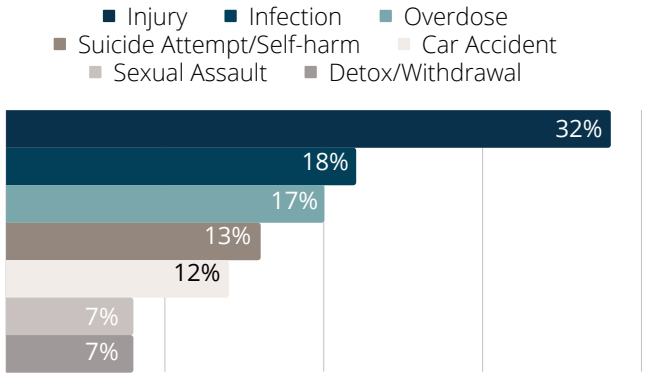


Fig 8. Reasons for SUD-related hospitalizations

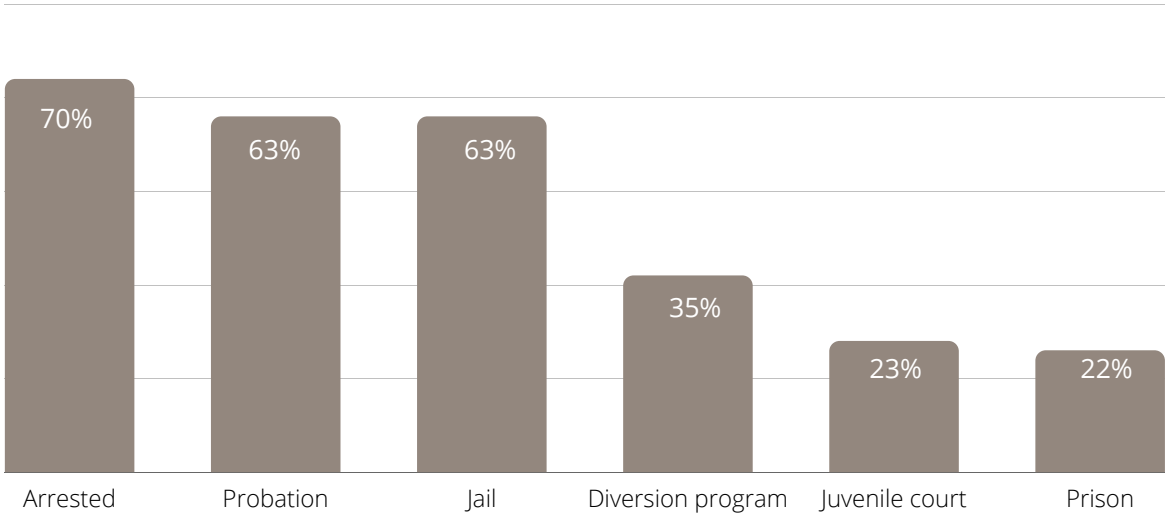


70% of patients report justice-involvement

Seventy percent of patients report justice involvement – 63% reported time in jail related to their substance use disorder, 35% participated in a diversion program, such as drug court, and 22% served time in prison.

One participant shared: "I was laying there sick from drinking just a couple days before I was pulled over for a DUI-DWI and I was praying to the Creator to help me because I don't want to be like this anymore to help me stop drinking and then it happened, I was pulled over on August 8th of 2020, I hated it at the time I was sitting in jail because I was going through withdrawals bad but I was also thanking God because I knew I was going to have to stop, I had no choice. I was immediately put on supervision probation and Wellness Court; I believe Wellness Court saved my life, if it wasn't for that, outpatient treatment and the recovery app, I would probably have drank myself to death. I couldn't stop drinking in fear of being sick from withdrawals."

Fig 9. Criminal Justice Invovlement

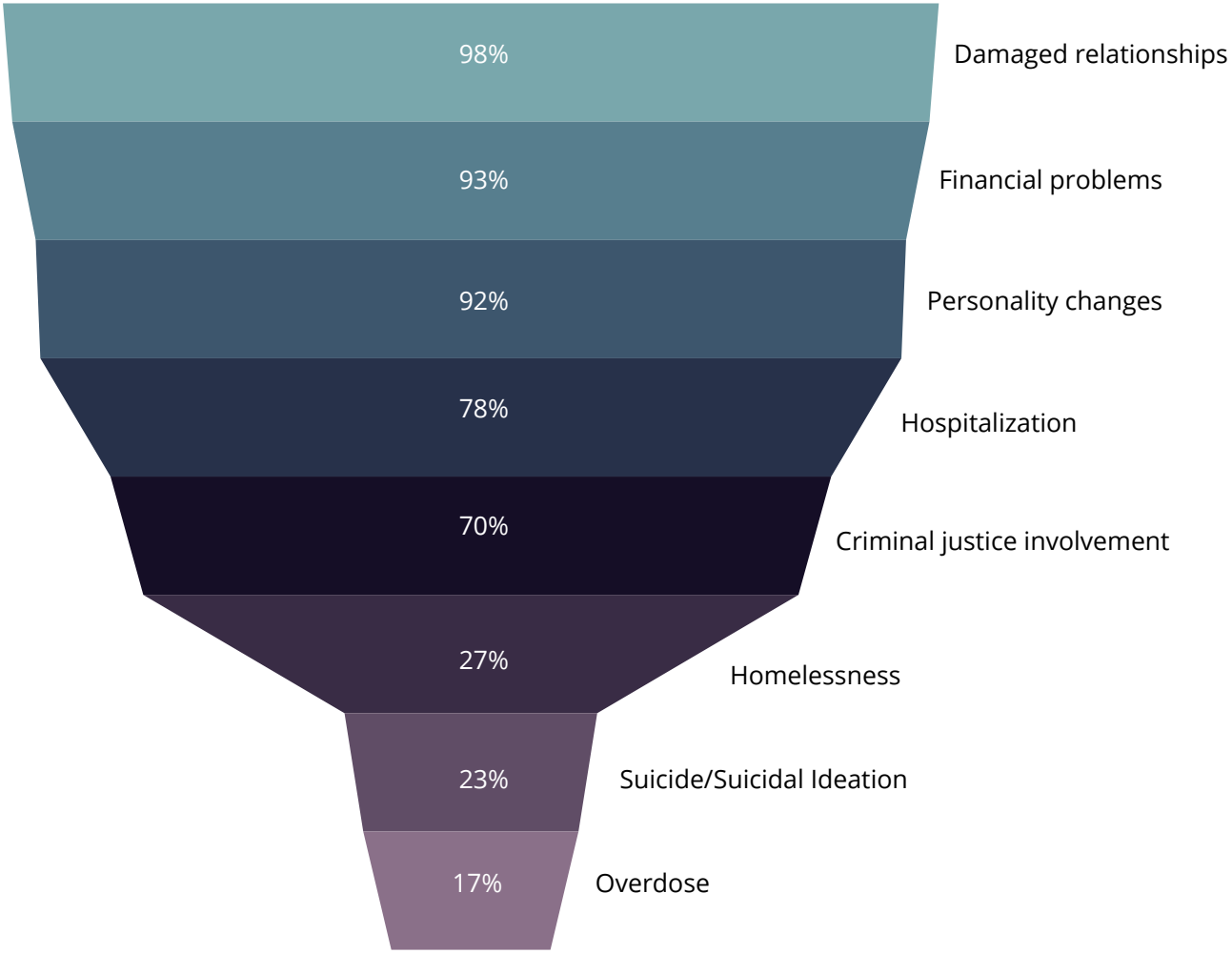


Damaged relationships and financial issues most frequent problems caused by substance use disorder

Signifiant problems caused by SUD were reported by patients, from damaged relationships, to personality changes, to financial problems.

One participant shared: "I did a lot of damage to my family, and myself, self-harm, when I would be in blackout drunk I would carve myself up with knives, I was just so full of hatred, and I was abusive to my ex-boyfriend. I never grew up, I never grew up. I didn't graduate high school, I couldn't keep a job. I just never matured mentally."

Fig 10. Problems Caused by Addiction



Patient Perspectives on Progression and Onset

"I think the reason I kept using substances was because I was trying to fill a void that was at the time unfixable. And it was also a social thing. I was trying to fit in with certain people."

"Well, when I had my first sip of alcohol that kind of unlocked something that made me want to do more."

"Well, to be honest, I mean growing up, I was a kind of an outcast. So I mean I guess like drinking made me feel confident and maybe relatable to other people and made me less self-conscious."

"It cost me my first marriage and my kid. I was in and out of prison from the time I was 18 until I was 60. I can't remember a time I wasn't on probation or parole. It's pushed away all my family away from me. It cost me my jobs. It robbed me of all my hobbies and things I love to do... I'm 61 and only now starting to live."

2 Trigger Events

Multiple trigger events contribute to the decision to get help

On average, patients shared three separate trigger events that contributed to engaging in treatment, a cluster of events that constitute the "Aha moment." The events weren't necessarily close in timing, but represented meaningful moments for the patients.

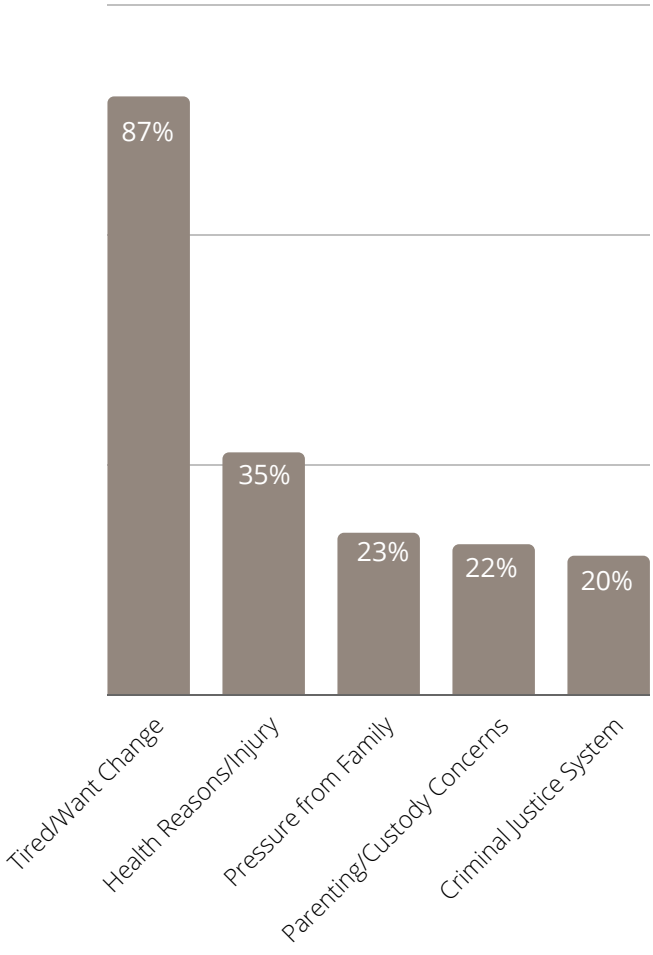
Tired, wanting change is the most common reason for engaging in treatment

The most prevalent reason for engaging in SUD treatment was tired/wanting change (87%), followed by health reasons (35%), pressure from loved ones (23%), parenting/custody concerns (22%), and pressure from the criminal justice system (20%).

> *I was sick and tired of being sick and tired.... I wanted my sobriety back, I wanted my life back, that's the bottom line.*

Another participant shared: "So what stopped me? I just couldn't do it anymore, I was 45. I'm like, what am I doing, you know, shooting dope in my 40's? I've lost everything again, everything. Everything fit in that syringe. My home, my life, my job, my dignity, it all went in there. And I just couldn't sacrifice all of that anymore."

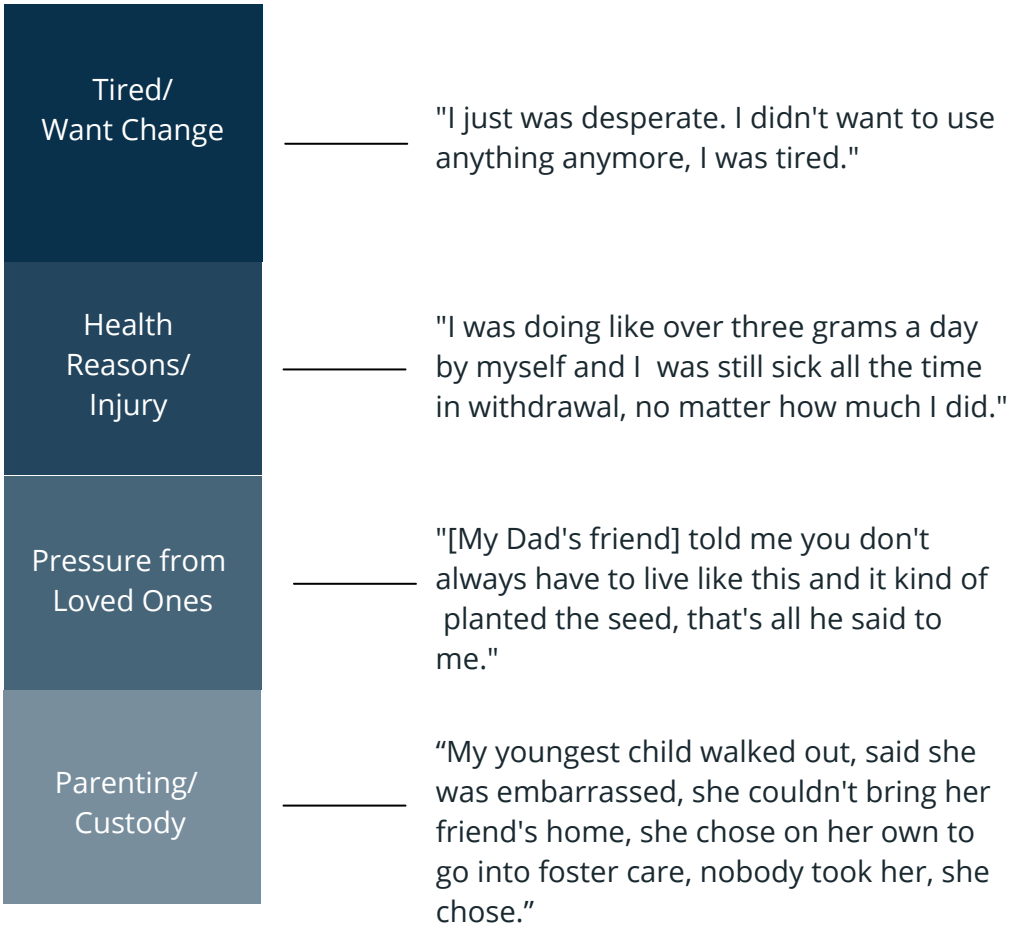
Fig. 11. Reasons for Engaging in Treatment/Recovery



Health reasons the second largest driver of engaging in treatment

Physical injury and health concerns were the second most common trigger events for participants. For example, one participant shared, "Two overdoses and had to go to an infectious disease doctor for hepatitis C." And another individual reported: "Bronchitis, and I was treated for sexual assault two times while under the influence."

Fig. 12. Patient input on trigger events



Children and family cited most frequently as the bright spots early in the process

Bright spots, or positive moments during the trigger events phase, included children and family, relief, hope for change, and encouragement from others.

Children & Family

"I didn't want to be separated from my daughter again and risk that being the cycle of her seeing me in and out of prison all throughout her life."

Relief

"It was just like relief -- I'm finally going to go do this."

Hope for Change

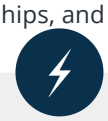
"Knowing that I was turning a new leaf and knowing that I was going from a very negative outlook and existence to looking forward to a very positive one."

Encouragement from Others

"My pastor called. When I told him I was going to get help and he was like I'm glad you did that. But that was the only bright spot."

Pain points: managing isolation and shame

Pain points, the difficulties and challenges faced during the trigger phase, included isolation, shame, lost relationships, and fear.



Isolation

"I was in jail, I was away from my kids, it was scary."

Shame

"Just so much shame. The word doesn't even encapsulate what that feels like you know. I had utter hatred for myself."

Lost Relationships

"I lost all my family, I had nothing to my name anymore, I finally realized the people that I was with did not care about me in the least bit. Yeah, I had nothing."

Fear

"Not knowing if I could do it, or like what my life would be like, if I entered recovery."

3 Getting Help

The help phase details the process that participants went through to research and identify services and resources for the treatment of their substance use disorder. This phase is largely marked by difficulties and barriers for patients.

Significant barriers encountered as patients try to find help

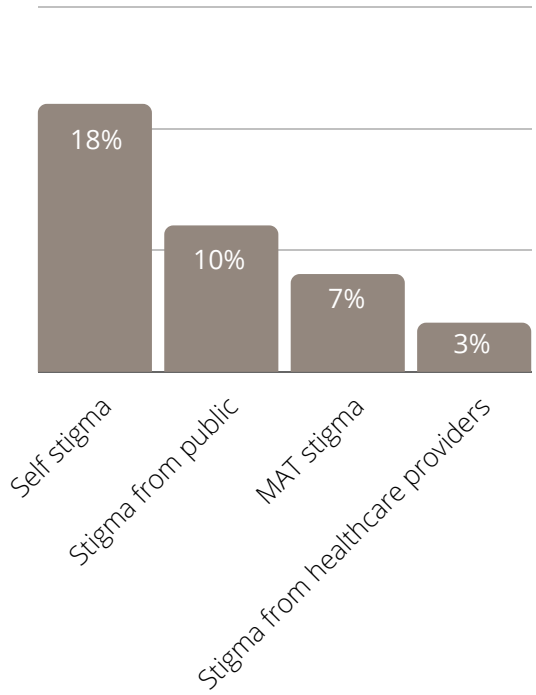
Patients identified the accessing help phase as extremely painful, disorganized, and difficult. Poor treatment access was a common experience among participants who experienced systemic barriers to addiction care, including high levels of stigma (32%); the complexity of navigating the substance use disorders care system (25%); wait times (20%); the high costs of treatment (8%); red tape payer policies such as fail first and prior authorization (7%); and transportation difficulties (5%).

High levels of stigma experienced by patients

Over 30% percent of participants cite stigma as a significant barrier during the process of finding help and treatment. Patients experience stigma from doctors and other healthcare professionals; stigma from families, friends and the general public, as well as experiences of self-stigma, which occurs when individuals internalize the stigmatizing beliefs and attitudes of the public and suffer negative consequences, including delayed treatment access.

> *"The stigma associated with substance use. I have track marks I can't change. I can't change the scars that I have on my body, but I still get judged."*

Fig. 13. Types of stigma experienced by patients



Stigma from healthcare providers is also a pain point for patients. One individual shared: “I think stigma is a really big one, though, just within myself, not with seeking help outside but in having to confront that I have this thing that is frowned on in society.”

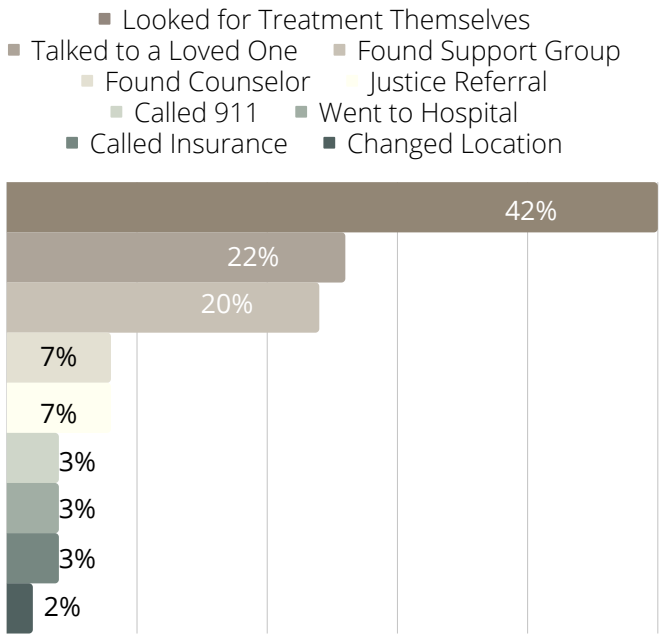
Barriers to Treatment

1. Stigma
2. Complexity of Navigating the Treatment System
3. Wait Times
4. High Costs of Treatment
5. Insurance Red Tape
6. Transportation Difficulties

Patients frequently search for services for themselves

During the getting help phase, over 60% of patients looked for services for themselves. 42% looked for treatment directly and 20% researched and found support groups to attend. Another 22% talked to a loved one/friend, 7% talked to counselor/mental health professional, 7% received a criminal justice referral, 3% called 911, 3% called their insurance company, and 2% distanced themselves from using location or moved back with family.

Fig. 14. How Individuals Found Treatment Services



The complexity of the system hampers treatment access

Feeling overwhelmed and confused about how to access treatment, repeated attempts to find treatment with no success, and frustration and agony over lack of access points frequent experiences among patients.

Another participant shared: "Well, I would have been probably in treatment a lot more times if I would have been able to find it some of the times when I looked and didn't have any means to get to it.”

> *So in my experience, I was not able to get help when I needed it or when I asked for it, begged for it.*

Significant difficulties waiting to access treatment

Long wait times and the pain and discomfort of withdrawal symptoms during that time were a consistent pain point for participants. One individual shared: “It took about a month to get it, though, so it didn't happen right away... that was a long month that was for sure.” Another participant remarked: "The wait, the wait time is long. I was in withdrawal, so the desire to leave and go, you know get well, was really strong."

> *You need a spot right then and if you don't have one right then, then tomorrow's probably too late. And I think that's the biggest struggle.*

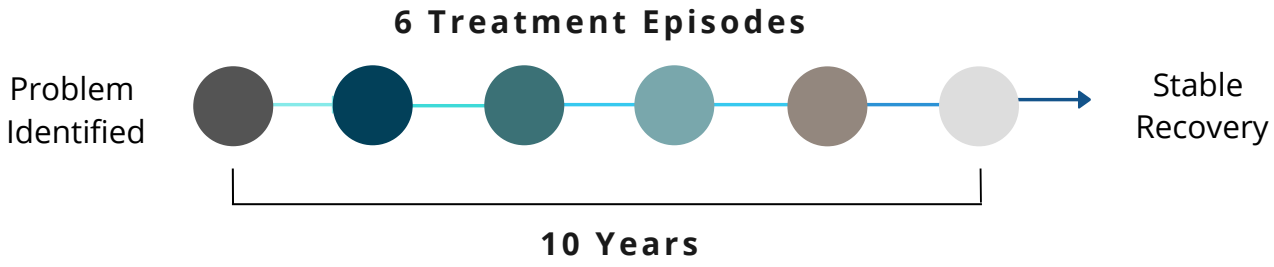
Problems navigating insurance

Participants noted difficulties navigating insurance. One individual shared: “Found it to be difficult navigating the insurance. Having to call back all the time and leave your name, because they want to know that you're really serious. And there wasn't a lot of choices, so there was really only one or two places in this town that I was from in Florida, and that was actually much bigger than where i'm at now but there wasn't Enough beds. You know so. That I remember that being a really huge challenge the phone.”

Average of 10 years of disease progression and 6 treatment episodes

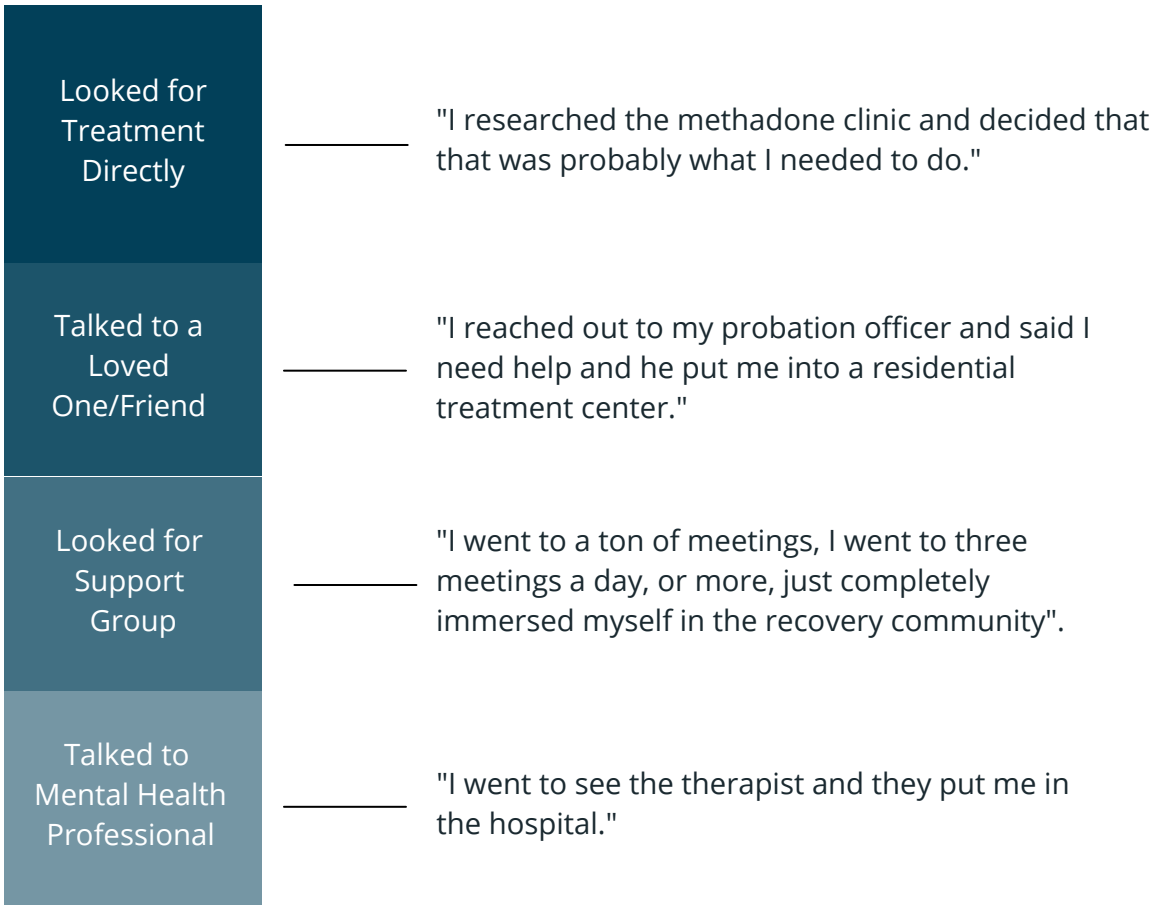
On average, patients report 10 years between realizing they have a SUD and finding recovery, participating in an average of 6 treatment episodes that had an additive, or cumulative effect in the success of the most recent treatment engagement. Previous treatment and recovery experiences, along with recommendations from friends, family, and a person's network, frequently form the basis for the treatment pathway selected.

Fig. 15. Average number of treatment episodes and length of time between patient realizing their SUD and finding stable recovery



Perspectives on most frequent ways patients get help

Fig. 16. Patient input on getting help



Friends and family in recovery a bright spot in the help phase

Bright spots included having family/friends in recovery, not feeling alone, finding a smooth transition into treatment, and finding a community. However, many patients reported no bright spots at all during this phase.

Friends/ Family in Recovery

"Well, my brother was in recovery, so I at least knew someone and didn't completely feel alone at that point."

Not Alone

"I was no longer alone, because I was in a group setting, so the loneliness dissipated."

Smooth Transition

"After the assessment I didn't have to wait a very long time. I think there was a sense of relief if that makes sense."

Finding a Community

"I started realizing that there's a lot of people in my community who are sober."

Waiting for access and managing withdrawal symptoms are pain points for patients

Pain Points included waiting for access, withdrawal symptoms, difficulty finding treatment, navigating insurance, financial barriers and family friends not being supportive.

Waiting for Access

"The wait, the wait time is long. I was in withdrawal, so the desire to leave and go, you know get well, was really strong."

Withdrawal Symptoms

"It was very difficult, the withdrawing and not being able to use because I couldn't [take a] hit."

Not Finding Help

“So in my experience, I was not able to get help when I needed it or when I asked for it, begged for it.”

Navigating Insurance

“I found it to be difficult navigating the insurance. And there wasn't a lot of choices, there wasn't enough beds."

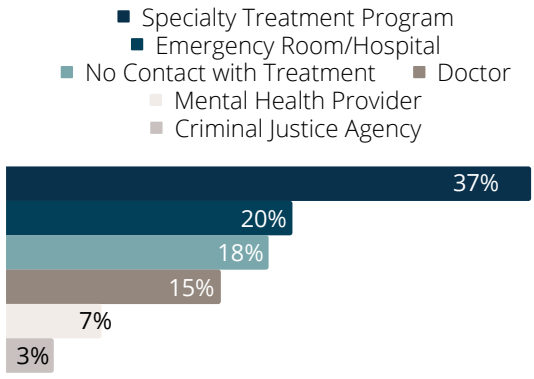
4 Care Begins

Most patients connect directly with specialty treatment providers

The care phase details the connection to treatment or other services, and the assessment process if applicable.

Previous experiences and treatment episodes guide the first contact and research conducted by patients. Direct engagement with a specialized treatment provider was the most often utilized first point of contact to find help (37%), followed by hospital or emergency room (20%), doctors (15%), mental health provider/counselor (7%), and criminal justice agencies (3%).

Fig. 17. Treatment access points



Of note, 18% of participants had no involvement with specialty treatment or recovery services and instead managed their symptoms and sobriety independently. On individual shared: "I had zero contact with the professional world when it came to my substance abuse."

Patients often fearful as care begins

Patients report strong emotions and high levels of uncertainty and fear as care begins. One participant shared: "I did have this mental breakdown in the intake process. Because I just like the revelation that, like my life was going to be changing, and I was also scared as well, so it's like a big mix of emotions and also I was coming down so there's an issue."

Stigma encountered in healthcare settings

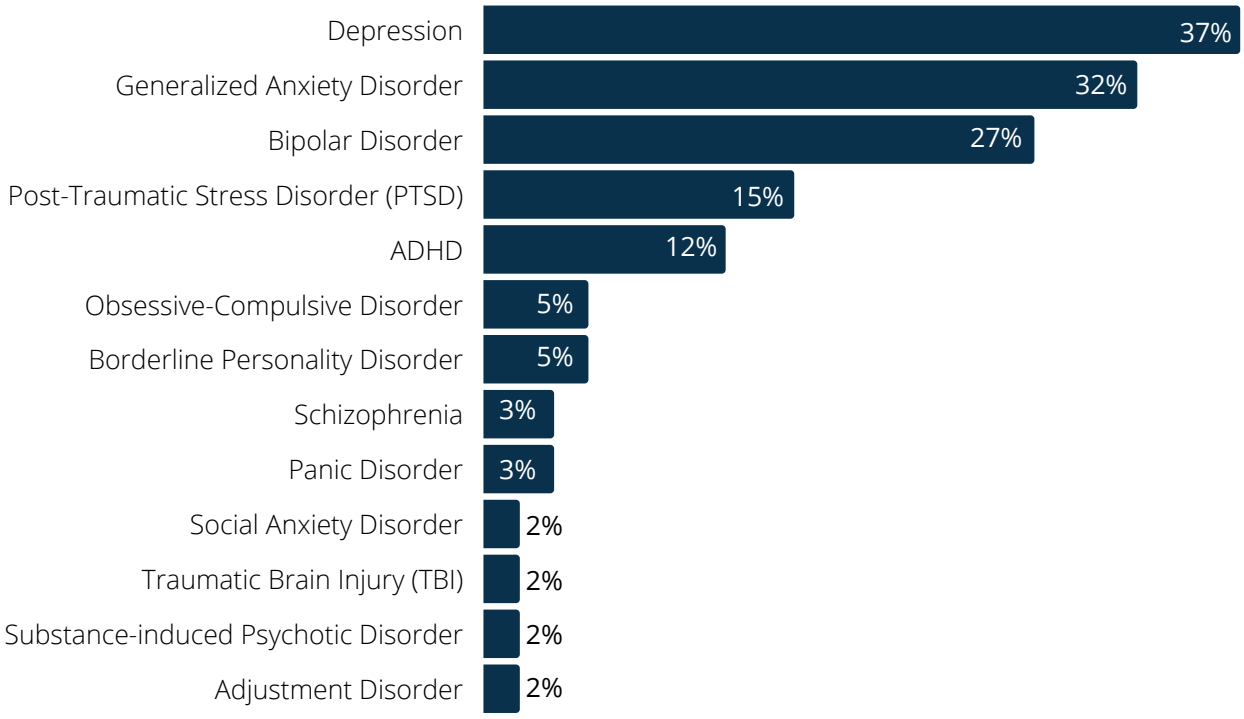
Feeling stigma from healthcare providers and other professionals during the care phase was a continued pain point for patients.

> *"I've experienced some medical providers, and it was just such a horrific experience, I never want to go there, even for recovery, because of how they treated myself and others. It was always about the shame. I always felt, no matter what it was, if I went in with a broken finger, or whatever, I was going to be treated with just such disdain."*

Co-occurring mental health disorders prevalent

While 68% of patients received a formal SUD assessment, assessments are also needed for co-occurring mental health disorders, physical health, and trauma, as 67% have a co-occurring mental health disorder. Depression, anxiety disorder, and bipolar disorder are the most common diagnoses.

Fig. 18. Mental health diagnoses reported by patients



Trauma experienced during active addiction

Trauma often experienced during active addiction, including physical violence and sexual assault.

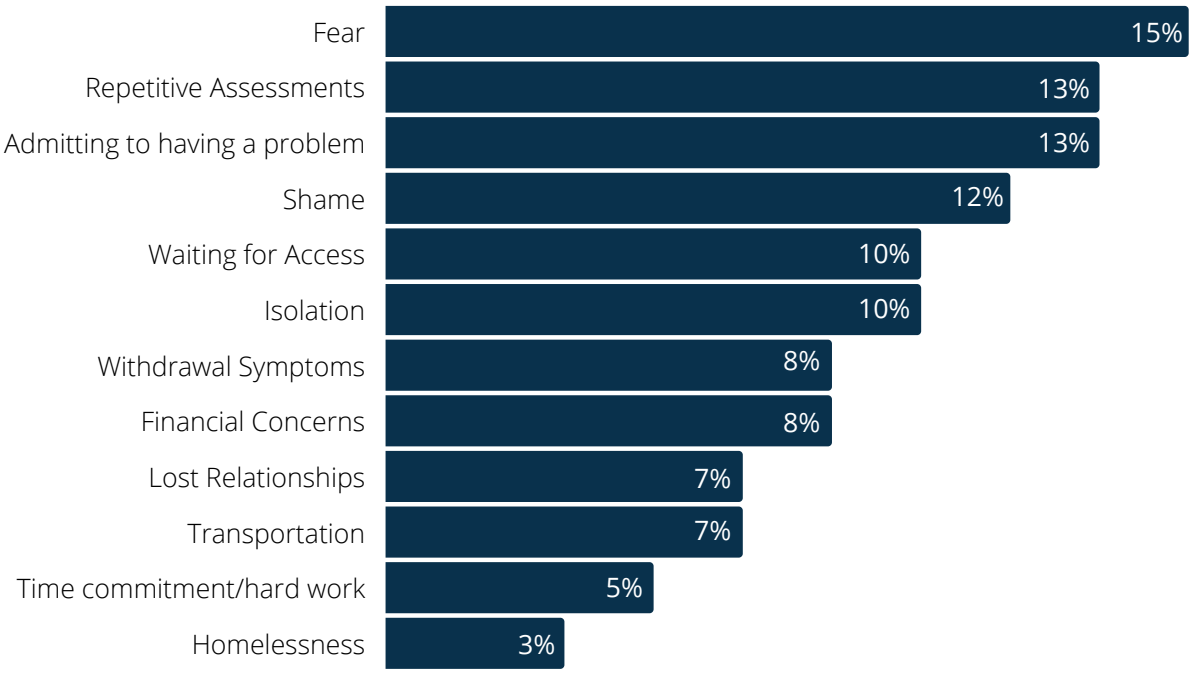
One participant shared: "Women, like me, are not supposed to make it, but we do and I think that we tend to judge and not support women that have made some of the choices I've made and been in some of the situations I've been in. I think that there needs to be more support and longer term care for women that are victims of sexual assault in childhood or otherwise, that have been in the sex industry, because it'll kill you. That have been victims of domestic violence, it's not just about getting clean, right? It's about healing this other trauma, there's a lot of trauma."

Patients report that repetitive assessments and interviews are triggering and difficult

A consistent pain point among patients was repetitive assessments and interviews during the care phase, with reports of feeling triggered and interrogated. Patients also questioned the utility of multiple interviews and the coordination of providers.

> *It was hard having to repeat everything I've been through like trauma, my addiction, everything like that, because every time you do an assessment you have to do it again. To tell another person. And I was just fearful, you know what I mean, like, Is this really going to work, is this worth my time.*

Fig. 19. Common pain points during care phase



Engagement with friendly providers and peers a bright spot in the care phase

Bright spots during the care phase include friendly engaging staff, peers/recovery coaches, and having employment and housing.

Friendly, Engaging Staff

"So there were people along the way that were just kind, and sometimes that was all it took."

Employment/ Housing

"I mean, I had a roof over my head. And I had a part time job. And I had the support of my family."

Peers/Recovery Coaches

“I think, for me, what kind of helped was the gentleman that I met at that treatment Center door...and he shared his experience with me. I identified with him."

Negative effects of repetitive assessments and isolation are frequent pain points

A consistent pain point among patients was repetitive assessments and interviews during the care phase, with reports of feeling triggered and interrogated. Patients also questioned the utility of multiple interviews and the coordination of providers. Additional pain points included isolation and feeling stigmatized.

Difficulty Repeating History

"The reliving my bottom, having to constantly re-discuss it ...was probably the roughest point of the assessments."

Isolation

"I still was living in my car. And I really thought that by signing myself into treatment that [my parents] would let me come home and that didn't happen."

Feeling Stigmatized

"Well, I definitely felt stigma, I definitely felt [the assessment] was long, it was way too many questions, it was like being interrogated. I just didn't have the mental capacity to endure that at that time because I felt so defeated and beat up and ashamed and guilty."

5 Treatment & Recovery

The treatment and recovery phase includes the diverse services and resources accessed by the patient, both within the healthcare system and outside.

Multiple services utilized, not a single intervention

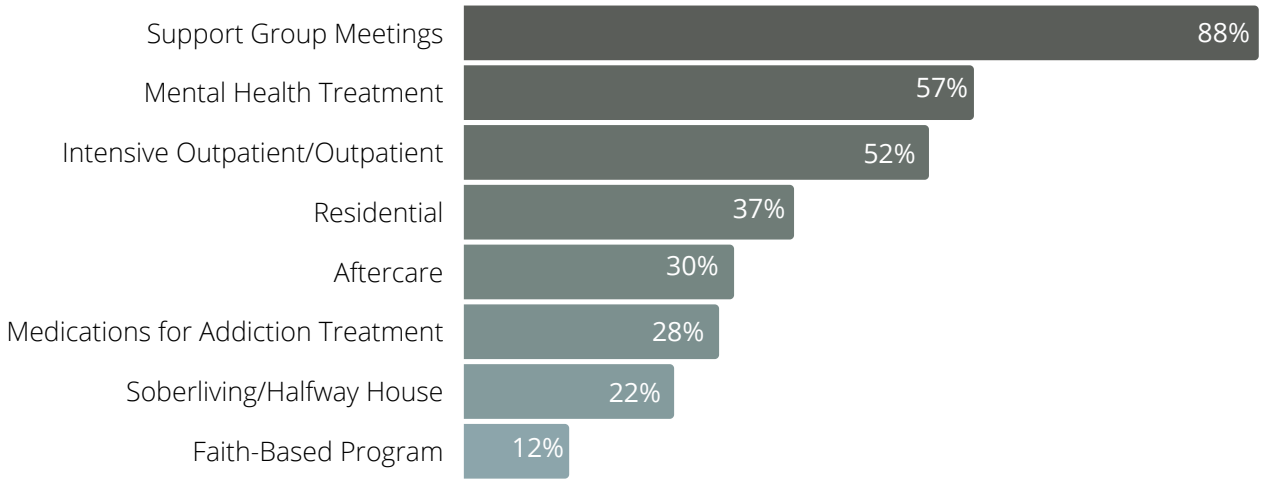
On average, patients utilized four different services for treatment and recovery support, not a single treatment or intervention. Services accessed were support groups (88%), counseling/mental health treatment (57%), intensive outpatient treatment programs (52%), followed by residential programs (37%), aftercare programs (30%), medications for addiction treatment (28%), sober living (22%), and faith-based programs (12%).

> *It was amazing... You realize you're not alone and you realize that it's, it really is a disease, and that you don't have to do it alone.*

Skills and tools from both current and previous treatment episodes helpful

Patients report that previous treatment episodes provided a foundation for treatment and recovery success. Rather than viewing previous episodes as a failure, the skills and tools learned accumulated over time.

Fig. 20. Treatment programs and services utilized



Layered interventions across three key domains – biological, psychological, and social

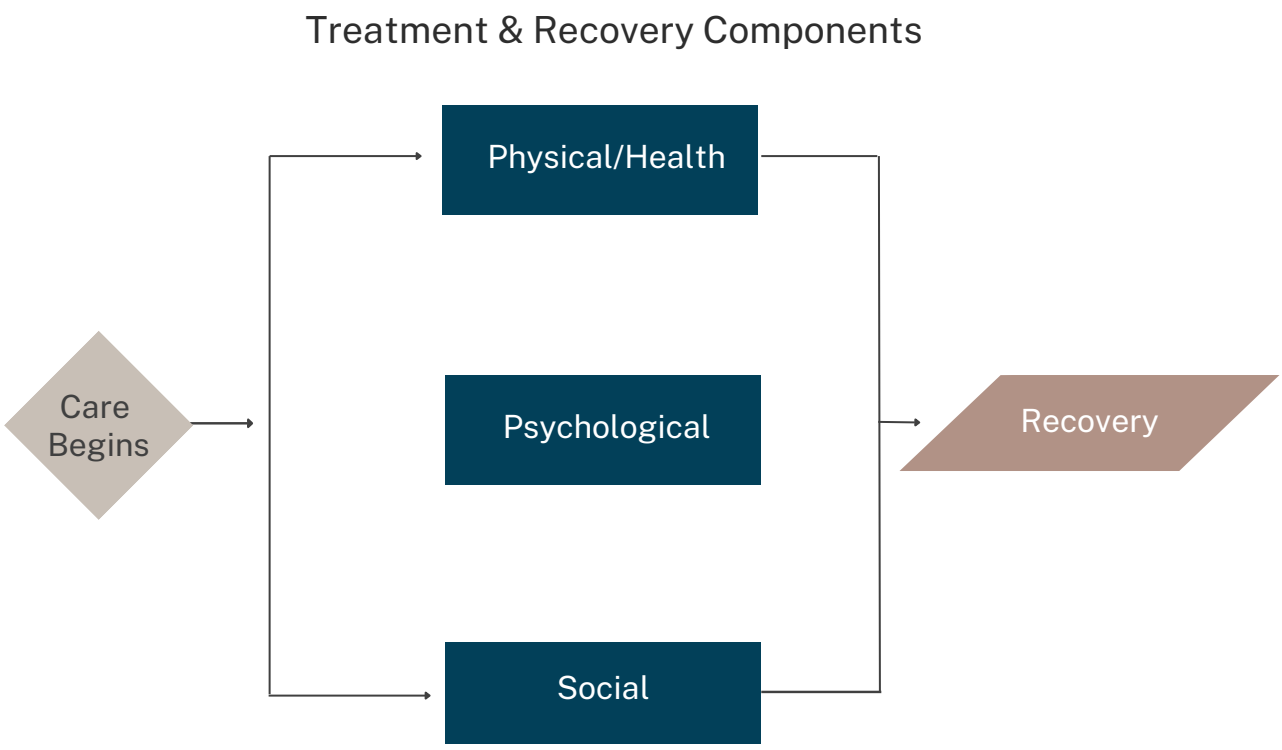
Patient feedback shows the need for layered interventions across three critical domains: 1) biological, or physical health, 2) psychological, and 3) social.

Biological interventions range from medications for addiction treatment, medical care for other health conditions, taking prescriptions for mental health disorders and other chronic conditions like heart disease and diabetes, as well as self care priorities that include sleep, exercise and proper nutrition. Forty-seven percent of participants utilized an intervention or service to address physical health.

Three out of four patients required psychological interventions. Psychological interventions include mental health counseling, group counseling, cognitive behavioral therapy, building a relapse prevention plan, identification and awareness of triggers for substance use to include high risk people, places and things, and skills and resource focused strategies like learning new coping skills.

Ninety-five percent of patients require social interventions. Social components include building a positive social network, commonly through support group participation, new hobbies and activities, and cutting out old friends and the individual's using network.

Fig. 21. Three domains of interventions needed



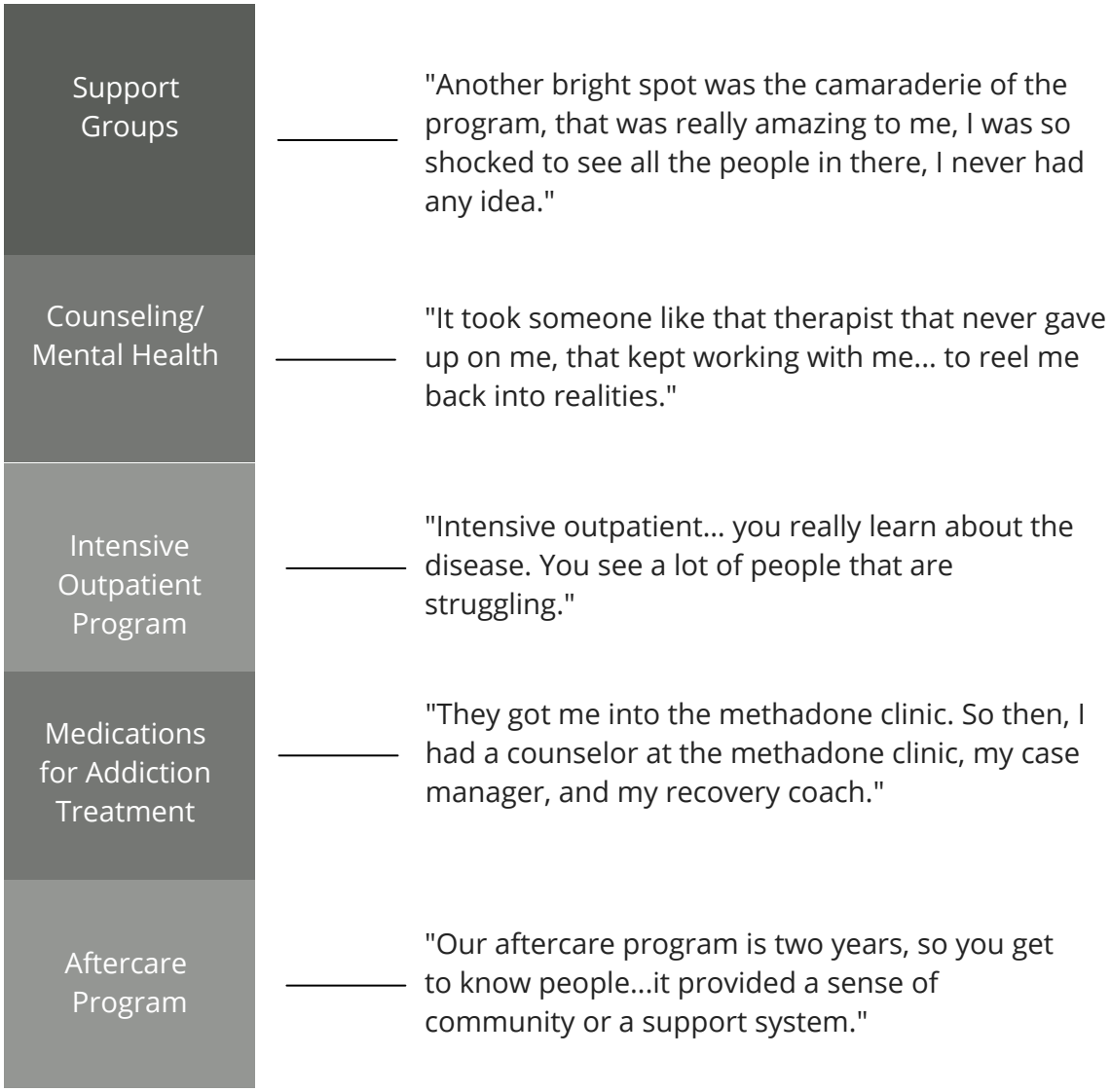
Low recovery literacy among healthcare providers creates challenges

A pain point in treatment for patients is encountering low recovery literacy among healthcare providers. Patients share the need to learn how to manage their chronic disorder, and frustration when selected providers are not well versed in the supports and layered interventions that are necessary to achieve stable recovery. Patient input suggests the need for a paradigm shift for SUD management to focus on empowering the person with an addiction to manage the disease successfully and to improve their quality of life.

Managing a SUD requires significant effort on the part of the patient. Whether education and services are embedded with care providers, linkage facilitators, handoffs to peer services, guidance from the primary SUD treatment provider on the components of managing the disease and skills and resources available is beneficial to the patient.

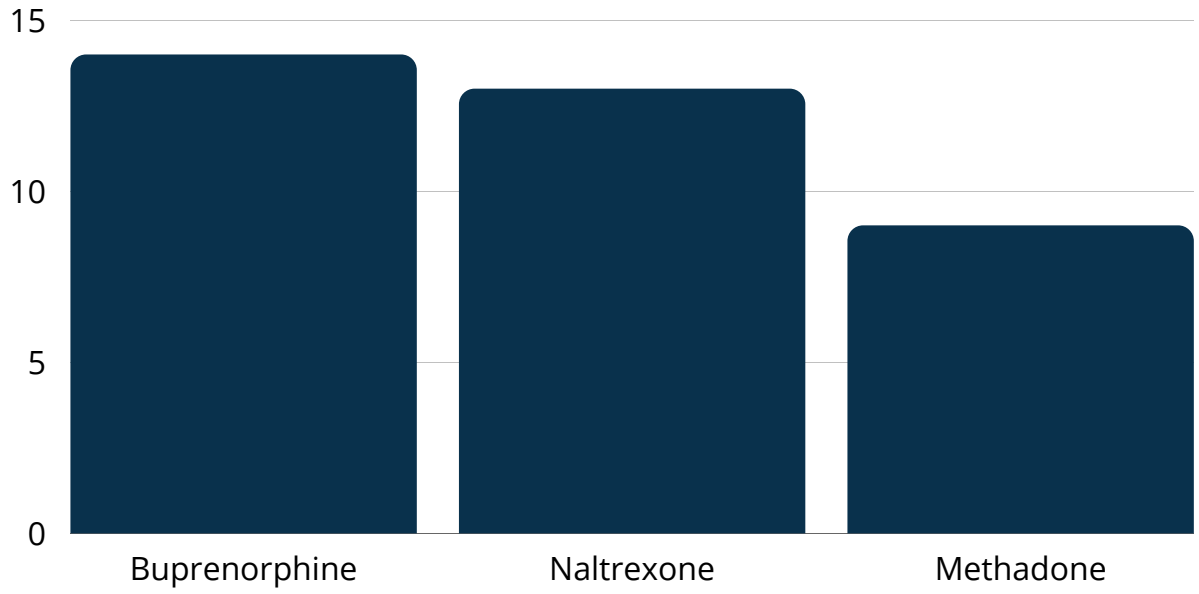
Encounters with providers without the knowledge to assist in the chronic disease management plan are difficult. One participant shared: “For me it really has to do with the level of care. When I first learned about suboxone I was literally just going to like what I could best described as a meat market, a place that you would go and you get your prescription. And that was it like as long as you had your money you could get the medicine and there was really no recourse for following treatment, so I really wasn't educated about my disease and what recovery was.”

Support groups, counseling and IOP most frequently accessed services by patients



Forty-five percent of participants utilized a medication for addiction treatment (MAT) at one point in their life. All three FDA-approved medications were utilized by patients -- Buprenorphine (52%), Naltrexone (48%), and Methadone (33%).

Fig. 22. Medications for Addiction Treatment Accessed



Low utilization of medications to treat alcohol use disorder

20% of patients with a primary alcohol use disorder (AUD) utilized an FDA-approved medication for AUD at one point in their life for treatment. Of the 30 AUD participants, 33% were prescribed Naltrexone, 20% Acamprosate, and only 10% of participants utilized Disulfiram.

Patient perspectives on MAT positive, though stigma around medication prevalent

Experiences with MAT were mostly positive, but the stigma around using medications created challenges for patients. One participant shared: "I guess stigma from other people, being on a MAT. I live in... like, it's not a big city. So I would say that this area for a long time has been indoctrinated in the 12 steps. And that includes like medical professionals, I went to my family doctor they wouldn't even entertain anything else other than getting off the methadone. They told me how bad it was and all kinds of things. And then my job, I mean, it was a struggle, because they of course didn't want anybody to know I was on it. And just from friends that weren't using but were in recovery they you know, had an issue with it."

Another shared: "Dealing with the anxiety and the you know all the guilt and shame from before my use so now I don't have that drug to numb me anymore um and. Honestly, a lot of it is a you know, probably people saying that you're not clean, you know i'm not really clean because i'm one method on so like i'm still using something, which I don't really like get to me, but you used to and then also the weight gain you know and people making fun of me for my weight because i've gained a lot of weight."

Bright Spots: Positive social connections and helpful clinicians

Bright spots included positive social connections, helpful clinicians, new tools and skills, learning about the disease, and peer/recovery coaches.

Positive Social Connections

"The social aspect of it because your first couple of years of recovery can be lonely because everyone you know you had to cut out of your life."

Helpful Clinicians

"The counselors call and check on you. The doctor calls and checks on you, even though it's not as often, but yearly he calls to see how you're doing "

New Tools and Skills

"You just learn how to deal with it, the tools that can help you to stay sober."

Learning about the Disease

"It was amazing... You realize you're not alone and you realize that it's, it really is a disease, and that you don't have to do it alone."

Peer/Recovery Coach

"My counselor for sure at treatment, she was actually in recovery herself and she really helped me."

Pain Points: Hard work and managing shame

Pain Points included the hard work/difficulty of treatment, managing shame and self-stigma, cutting out friends/old networks, transportation challenges, and unhelpful home/work environments.

Hard Work/ Difficulty

"It was hard and a lot of work, I mean just the honesty that's required and being honest with myself. I had a problem, but really confronting it doing something about it was what's difficult."

Managing Shame/Self Stigma

"Facing the past, walking through the things... overcoming my identity and how I saw myself and pushing through those things were very painful, it still is every day."

Cutting out Friends/Old Network

"The most painful thing in the beginning, was that I lost people I thought were very close to me and really cared about me. So the painfulness was the realization that drugs are what bound me to a lot of people."

Transportation Challenges

"Riding the bus- I had to take two buses to get there. Sometimes, it was a long day to go to work and then go to treatment and sometimes I was super tired."

Unhelpful Home/Work Environment

"I was in intensive outpatient so it was difficult to be going home or working in an environment where you know, drugs and alcohol were present, you know. So that was challenging, just feeling triggered."

Patient perspectives on treatment and recovery

“It took someone like that therapist that never gave up on me, that kept working with me... to reel me back into realities.”

"The social aspect of it because your first couple of years of recovery can be lonely because everyone you know you had to cut out of your life."

"The most painful thing in the beginning, was that I lost people I thought were very close to me and really cared about me. So the painfulness was the realization that drugs are what bound me to a lot of people."

“Facing the past, walking through the things.. overcoming my identify and how I saw myself and pushing through those things were very painful, it still is every day.”

“The brightest spot was learning that I'm not the gangster, the monster, the bad guy I've been perceived as all my life. That I'm really, a good guy. And I'm really not cold hearted and totally against authority and people, but I really love people and I love helping people that's my biggest thing. Getting to know myself, ditching a lot of my fears, having a stable environment to live in and not be homeless, there are so many, there are so many, but the main thing is getting to know myself and getting to know God.”

6 Lifestyle Changes

Engaging in treatment and lifestyle modifications are concurrent, not sequential, in finding stable recovery

Lifestyle changes are cited by patients to be as critical to success as treatment and recovery services. Patients share that the things encountered every day play a critical role in supporting or hampering recovery.

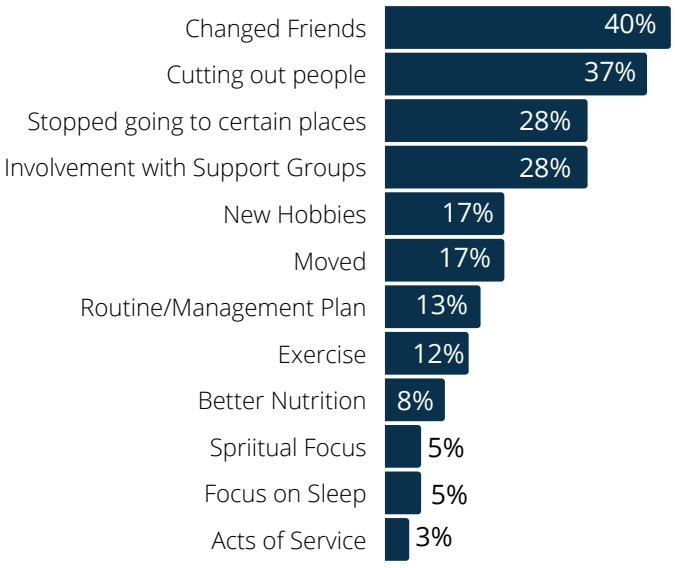
Building a positive social network a critical lifestyle change

Creating a positive, supportive social network is a dominant feature of successful recovery, along with avoiding individuals, places, and other triggers that present memory and physical cues to resuming substance use (i.e. using friends, bars, parties, concerts, boredom.) The exact constellation of triggers is unique to each patient.

Common lifestyle modifications include avoidance of high-risk people, places, and things (42%), changing friends (40%), becoming honest open-minded and accountable (25%), self-care such as exercise, nutrition, and sleep (23%), and developing a consistent routine (13%).

> *Cutting out people. Staying around healthier people. I had to stay busy. Going into the gym. Finding some kind of routine that was hard. the courage to go to meetings like I was traveling an hour and a half to go to meetings, because I was afraid to go to meetings my area.*

Figure 23. Most Frequent Lifestyle Modifications



Patient input on lifestyle modifications

Avoiding Risky People, Places, and Things	"Well I moved, out of state, changed my people, places and things, changed routine and old habits, changed things that I did in my spare time."
New Friends	"I had to change the people that I associated with and talk to in my life, I literally had to move away from my home to get sober."
Selfcare: Exercise, Nutrition, Sleep	"I started changing my health. I started working out more often and eating better. Just kind of taking care of myself."
Honesty and Accountability	"I had to be honest with myself and my family about my addiction, because I kept that a secret for a long time. I had to let them in."
Routine/ Daily Management Plan	“The most important thing you can do for your addiction to to overcome your addiction is to get into a routine and you know 30 days in a rehab doesn't get you in a healthy routine like people think. It takes months and months, if not a year.”

Finding a community and feeling happy again are bright spots for patients as they manage lifestyle changes

Bright spots include creating a positive support network, feeling happy again, being present in life again, being reunited with children/family, and feeling physically healthier.

Friendships/ Support Network

"Sense of belonging, getting to know a good group of people or community."

Feeling Happy Again

"Finding joy and the excitement to know that I do have a purpose and the possibilities are infinite."

Being Present in Life Again

"It was appreciating things that I didn't appreciate for a long time, things like being outside and the nice weather and hearing the birds singing..."

Reunited with Children/ Family

"Just being clean again, having goals again, being around people that I loved and that loved me was really healing. Just being clean, just delicious, it's wonderful."

Physically Healthier

"I feel like the changes that I made were just kind of self-care as far as like going to therapy...eating healthy, doing exercise, you know, taking care of myself talking to a sponsor, doing step work."

Difficulty making amends and stigma around medications are pain points for patients

Frequent Pain Points include difficulty making amends, triggers associated with high-risk people, places and things, MAT stigma, trouble sleeping, and sadness/depression.

Difficulty Making Amends

"Dealing with the consequences of things that I did in my addiction and cleaning up the mess that I made. The trust within my house- my family didn't trust me at all."

Triggers: People, Places & Things

"Knowing people, places and things were a huge part of my recovery, as well as knowing that if I wanted to be in recovery and stay in recovery, I had to cut a lot of people out of my life and make better choices."

MAT Stigma

"I guess stigma from other people for being on a MAT. I went to my family doctor and they wouldn't even entertain anything else other than getting off the methadone."

Trouble Sleeping

"I couldn't sleep anymore, I was so uncomfortable. I remember just kicking around in my bed for hours and hours and hours, and that was really painful."

Sadness/ Depression

"Man I dealt with a lot of mental health stuff...like severe depression and suicidal thoughts and stuff like that. It wasn't pleasant at all."

> *This feeling of worth and a feeling of accomplishment for what I've done…it makes you feel good about yourself.*

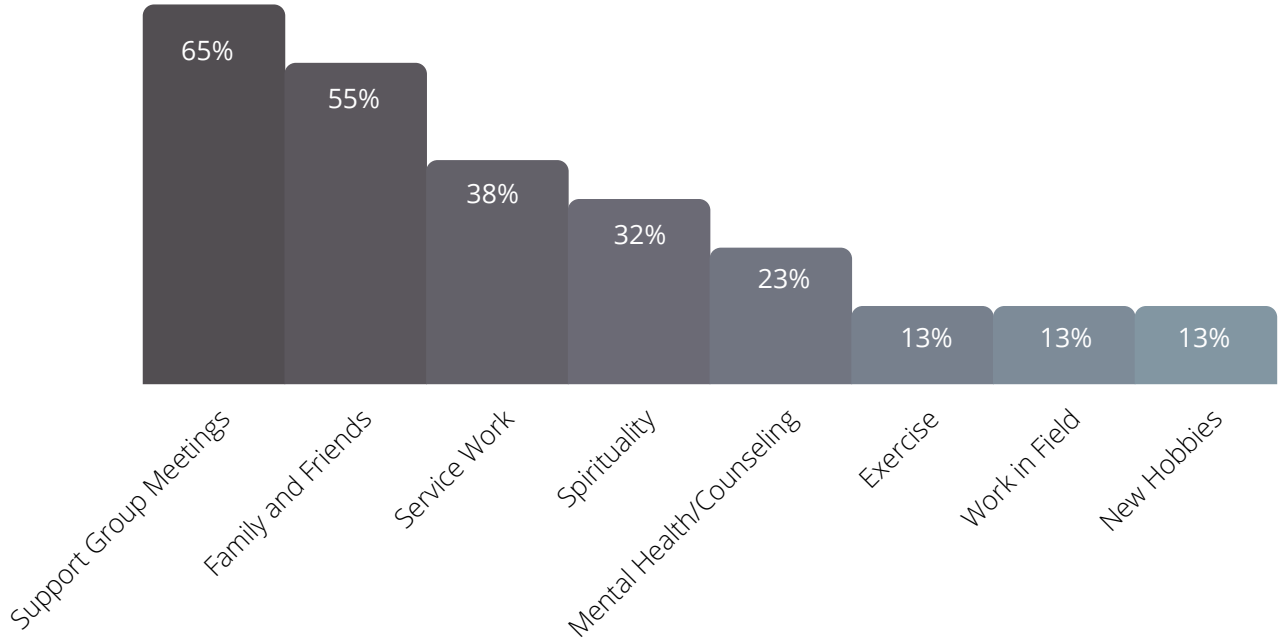
7 Ongoing Support

An average of 3 services utilized for ongoing support

Participants shared that they rely on multiple supports in long-term recovery with an average of three services utilized. The most common services were support groups (65%), family and friends (55%), volunteer and service work (38%), and mental health/counseling (23%). Patients in recovery from SUDs continue supports specific to their needs for years or even decades.

> *I still go to meetings every week, I got a sponsor, I'm working the steps, I'm doing a new round of steps on the domestic violence. I have a whole group of friends, I'm active, I eat really really well, I think that's a big part of it, I think we can become really addicted to food, I had to lose 40 pounds, I love the work I do, just my mind body and spirit. The whole thing.*

Fig. 24. Activities and Services Utilized in Long-Term Recovery

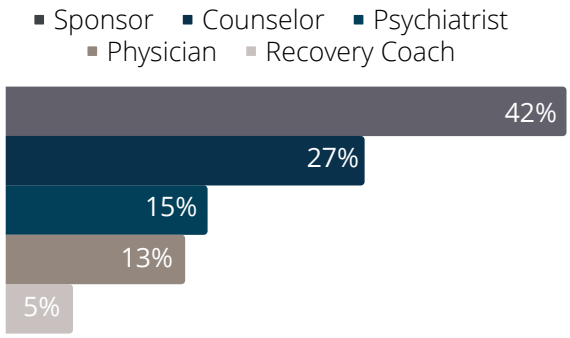


Over half of patients work with a sponsor or professional to help manage their recovery

58% of patients report having a physician, recovery coach or other professional to help manage their recovery.

- 42% have a sponsor
- 27% see a counselor
- 15% see a psychiatrist
- 13% see a physician
- 5% have a recovery coach

Fig. 26. Sponsors, Coaches, Mental Health Professionals Accessed in Long-Term Recovery



Patient input on supports in long-term recovery

Support Groups	"I actually enjoy going to my meetings now, they're a part of my day, I go to meetings every day,"
Volunteer & Community Service	"I go every month back to the homeless shelter. That's one of my biggest joys... getting to share my inspiration with other people."
Mental Health/ Counseling	"So my therapist is huge in my recovery."

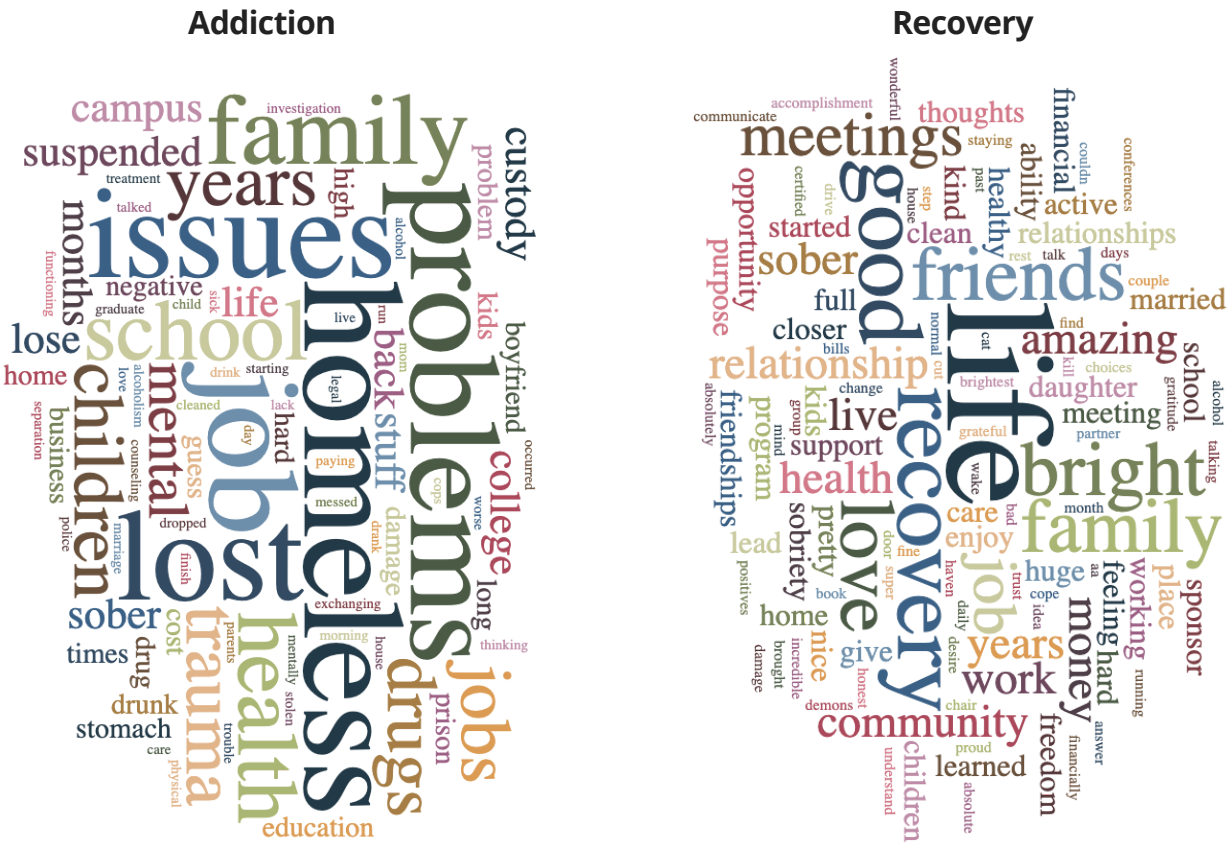
> *I love being able to have a life that I couldn't have dreamed of over seven and a half years ago. I love the freedom I love the serenity the piece that I have I love that I have skills today that I can use when i'm having a really good day or really bad day. I have a sense of purpose and meaning that large accounts from my own spiritual beliefs and practices that never had before. The obsession to want to use has left me.*

Before and after: active addiction to stable recovery

Analysis of 60 life course history interviews conducted during the study showed specific themes from onset, progression to treatment and recovery.

A word cloud is a visual representation of word frequency where the more commonly used terms in the analyzed text appear larger in the visualization. Themes and tags relevant to active addiction included homelessness, job loss, trauma, children and custody issues, health challenges, school suspension and expulsion, negative impact on friends and family. In contrast, common themes related to recovery include improved relationships, experiencing life, freedom, health and wellness and words like good, love and amazing.

Fig. 25. Word Cloud of Key Themes from Before and After Treatment



Having a full life and the feeling of accomplishment are bright spots in recovery

Having a Full Life

"I have full custody of my daughter...I bought a house, I'm gainfully employed, I can drive a vehicle legally....friends, family."

Feeling of Accomplishment

"This feeling of worth and a feeling of accomplishment for what I've done...it makes you feel good about yourself."

Healthy Relationships

"Restoration with my oldest daughter, just closer relationship with my dad and youngest daughter, just an overall feeling of relief and health and gratitude."

Health consequences and limited access to services are pain points

Health Consequences

"I don't want to be a heart patient, I don't want to be limited on anything. But those are the choices I made in my addiction."

COVID

"Challenges include obviously the COVID thing. I don't want to go to meetings in person, because the people that are in person don't seem to care about COVID."

Limited Access to Services

"In this rural area I'm finding support groups are very limited and if you're a multiple pathway person it's even more limited."

> *I guess I will say it's not over, even though I am in recovery, the journey is still not over. I feel like there's still always room for improvement in recovery and you can always do better, you can always try to improve yourself. Also there are still things within myself I know I have to work on and that's my biggest issue is working on my inner self and getting me to the point where I don't feel like I need pain pills to help me with the way I feel or to not feel anything at all.*

8 Ways Forward

Key next steps based on the findings of this report include:

1. Reduce barriers to treatment

Patients encounter systemic barriers to addiction care, including long wait times; high treatment costs; and red tape payer policies such as fail first and prior authorization. Patients require assistance navigating the substance use disorders care system, determining evidence-based care options, and support for the management of the chronic condition.

2. Improve training for healthcare providers

Research has found that individuals who experience stigma due to an SUD are more likely to continue engaging in substance use, and manifest greater delayed treatment access and higher rates of dropout. Patients in the study shared the difficulty of interfacing with healthcare professionals with stigmatizing beliefs and attitudes. Efforts to decrease stigma should include increasing addiction literacy levels to counteract education gaps and misconceptions about SUDs. Patients also shared better outcomes working with treatment providers trained in addiction who can help patients establish a long-term management plan.

3. Streamline the assessment process

Patients share the tremendous discomfort and trauma of repetitive assessments and interviews when accessing treatment. Responses include feeling triggered and interrogated and questioning the utility of multiple interviews. Clinicians can streamline the assessment process and share information with other providers.

4. Individualized care and management plans needed

The majority of patients utilize multiple services for treatment and recovery support, not a single treatment or intervention. Patients on average utilized four services during treatment and three in long-term care management. Lifestyle modifications, such as building a positive social network and discontinuing contact with those still using substances, are critical elements of recovery stability. More education for both patient and providers is needed to reinforce the individualized, multi-faceted management plans needed.

5. Screen for ACEs

Most patients have experienced multiple adverse childhood experiences, particularly living in a household with SUD. Evidence-based prevention strategies are available and yet underutilized, including screening, early intervention, programs to address ACEs and children impacted by parental substance use disorder, as well as primary prevention interventions. Preventing the development of substance use disorders must be a priority and can change the trajectory of the crisis.

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