

Review of the effects of self-stigma and perceived social stigma on the treatment-seeking decisions of individuals with drug- and alcohol-use disorders

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Abstract: Substance-use disorders are a public health crisis globally and carry with them significant morbidity and mortality. Stigma toward people who abuse these substances, as well as the internalization of that stigma by substance users, is widespread. In this review, we synthesized the available evidence for the role of perceived social stigma and self-stigma in people's willingness to seek treatment. While stigma may be frequently cited as a barrier to treatment in some samples, the degree of its impact on decision-making regarding treatment varied widely. More research needs to be done to standardize the definition and measurement of self- and perceived social stigma to fully determine the magnitude of their effect on treatment-seeking decisions.

Keywords: self-stigma, perceived social stigma, substance-use disorders, treatment seeking

Introduction

Alcohol-use disorders (AUDs) and drug-use disorders (DUDs) are issues of great concern to public health officials around the world. According to the *World Drug Report*, 31 million adult drug users across the globe suffer from a DUD, and the number of deaths from drug overdose has been rising.¹ Indeed, in the USA alone, deaths from overdoses of heroin or other opioids have quadrupled since 2010.² Although much of this trend is attributable to increases in the use of pharmaceutical opioids, legal substances, such as alcohol, are also problematic. Globally, 16% of individuals 15 years of age or older reported participating in episodes of heavy alcohol consumption in 2014, and 5.9% of all deaths that year were caused by alcohol use.³ In the USA, 15.1 million adults over the age of 18 years had an AUD in 2015.⁴

Despite the potentially lethal consequences of DUDs and AUDs, it has been estimated that fewer than one in six individuals worldwide receives treatment each year.¹ Within the USA, the National Epidemiologic Survey on Alcohol and Related Conditions estimated that rates of treatment seeking during the first year of disorder onset were 13% for drug dependence, 2% for drug abuse, 5% for alcohol dependence, and 1% for alcohol abuse.⁵ Previous work has identified a number of treatment barriers that contribute to these low utilization rates. These barriers include systematic issues (ie, features endemic to the health care system), such as high costs of treatment, poor coordination among health care providers, inconvenient service hours, delays in access (ie, lengthy waiting times to see providers and lengthy waits for acceptance into treatment programs), and shortages of programs.^{6–13} Nonsystematic treatment

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barriers (ie, characteristics of individuals rather than the health care system) include denial of a problem,^{8,14–16} lack of knowledge of treatment options,^{6–9} and dislike of available treatment options stemming either from doubts about the treatment model being offered or the perceived daily burden of participating in treatment.⁶ Perceived burden is a particularly common complaint among opioid users in methadone maintenance treatment, which requires a daily time commitment to participate successfully.¹⁷

One type of barrier that is believed to be particularly impactful for those in need of treatment for AUDs and DUDs is stigma. Stigma is a complex construct that can come from many sources and may manifest as a barrier in several ways. Perceived social stigma is one type of stigma in which a person recognizes and believes that their society holds prejudicial beliefs that will result in discrimination against them.¹⁸ Perceived social stigma can act as a systematic barrier when those to whom substance users turn for help (eg, primary-care providers) react with negative judgments and even disgust. Indeed, there is evidence not only that primary-care providers do not feel prepared to deliver appropriate care to those with substance-use issues, such as AUD and DUD,¹⁹ but also that health care professionals in general may have negatively biased views of these individuals that include beliefs that such individuals are violent, manipulative, and poorly motivated to change.²⁰ Such reactions to substance users may be so subtle that they are felt by the substance user, but are otherwise ineffectual, or they may be accompanied by more direct disparities in care (eg, differential care patterns after acute myocardial infarction).²¹ These attitudes may also directly impact the behaviors of drug and alcohol users, as research has shown that individuals who experience discrimination are much more likely to engage in behaviors that are harmful to their health.²² Finally, perceived social stigma may become internalized and result in self-stigma (ie, the personal endorsement of stereotypes about oneself and the resulting prejudice and self-discrimination).¹⁸

Various types of stigma can also act as nonsystematic barriers. Public stigma against substance abuse is common²³ and can deter people with a variety of mental health conditions, including substance-related conditions, from seeking help, due to feelings of embarrassment or shame.^{1,5,16} Self-stigma can also deter treatment when it results in loss of self-respect and questioning the point of trying to get better.²⁴ At least one review has found that attitudinal barriers, a category including stigma, were more important in predicting nontreatment than financial barriers.²⁵ However, note that this review was limited in scope to papers produced from one nationwide longitudinal

study, while there have been a number of other studies that have examined this issue. The purpose of the current paper is to provide a broader review of the literature examining the impact of perceived social stigma and self-stigma on treatment-seeking decisions, including expressed desire to enter treatment.

Methods

Search strategy

A systematic search of the literature was carried out to identify articles related to perceived social stigma and self-stigma related to seeking treatment for AUDs and DUDs. The PubMed, Scopus, and PsycInfo databases were searched first in September 2016. Our initial search used the following terms: (“social stigma” OR self-stigma) AND (dependence, addiction, OR abuse). We then expanded our PubMed search by adding the MeSH terms “shame” and “substance-related disorders”, producing the following search string: (“shame” [MeSH] OR “social stigma” OR self-stigma OR stigma) AND “substance-related disorders” (MeSH). We then also expanded our PsycInfo and Scopus searches to the following: (shame OR “social stigma” OR self-stigma OR stigma) AND “substance-related disorders” OR “drug abuse” OR “drug dependence” OR “alcohol abuse” OR “alcohol dependence” OR addiction OR “substance abuse”. References identified within publications and thought to be relevant were added to the corpus of articles for further screening. Due to the time lapse between the initial search and finalization of the manuscript, the search was repeated on July 27, 2018.

Selection of literature

After discarding of duplicates and articles not available in English (due to lack of translation resources), at least two people examined the title and abstract of each article for relevance to the review questions. Next, the bodies of the remaining papers were reviewed. Opinion pieces, conference abstracts, case reports, case series, commentaries, and review articles or book chapters without original research reported were excluded, as were studies that did not have people who used psychoactive substances as subjects or that did not explicitly link social or self-stigma to treatment seeking. We included articles that were original empirical work and explicitly linked stigma (of any type, as terminology varied or was vague in many studies, ie, did not specify a type of stigma) or stigma-like constructs (ie, shame,¹ embarrassment, need for secrecy) to either the desire to seek treatment or actually seeking treatment for alcohol or drug use. Stigma-like constructs were included because in many articles stigma was a loosely defined concept that was discussed in terms of

being ashamed or embarrassed for others to find out about problematic drug or alcohol use, but not necessarily precisely worded during measurement. We also included both articles that specified diagnoses of AUD or DUD and those that referenced problematic alcohol or drug use in the absence of an official diagnosis. We did not screen articles based on the legality of the substance. We did exclude studies that looked solely at nicotine dependence, as this was not the target of this review. Because we aimed to be as inclusive as possible, we did not exclude articles based on quality of evidence, but rather critiqued articles as appropriate in our analysis.

All authors participated in initial screening before the primary author and KC reviewed them again to ensure completeness. Disagreements, if any, were resolved through discussion and consensus. The PRISMA flowchart for selection of articles is shown in Figure 1.

Data extraction

Tables 1 and 2 contain overall summaries of all articles. For each article, we extracted reference information, location, sample size, participant demographics, relevant constructs measured in the study, and results relevant to this review. For qualitative articles (Table 1), we extracted analysis approach, while for quantitative articles (Table 2), we extracted construct-measurement tools.

Results

Figure 1 illustrates the literature-identification and -screening process. Of 6,139 articles considered, 64 were included in the final review. A total of 31 qualitative articles are summarized in Table 1, and 33 quantitative articles are summarized in Table 2. Note that “perceived stigma” is based upon subjective reports, and thus does not bear on this issue of whether

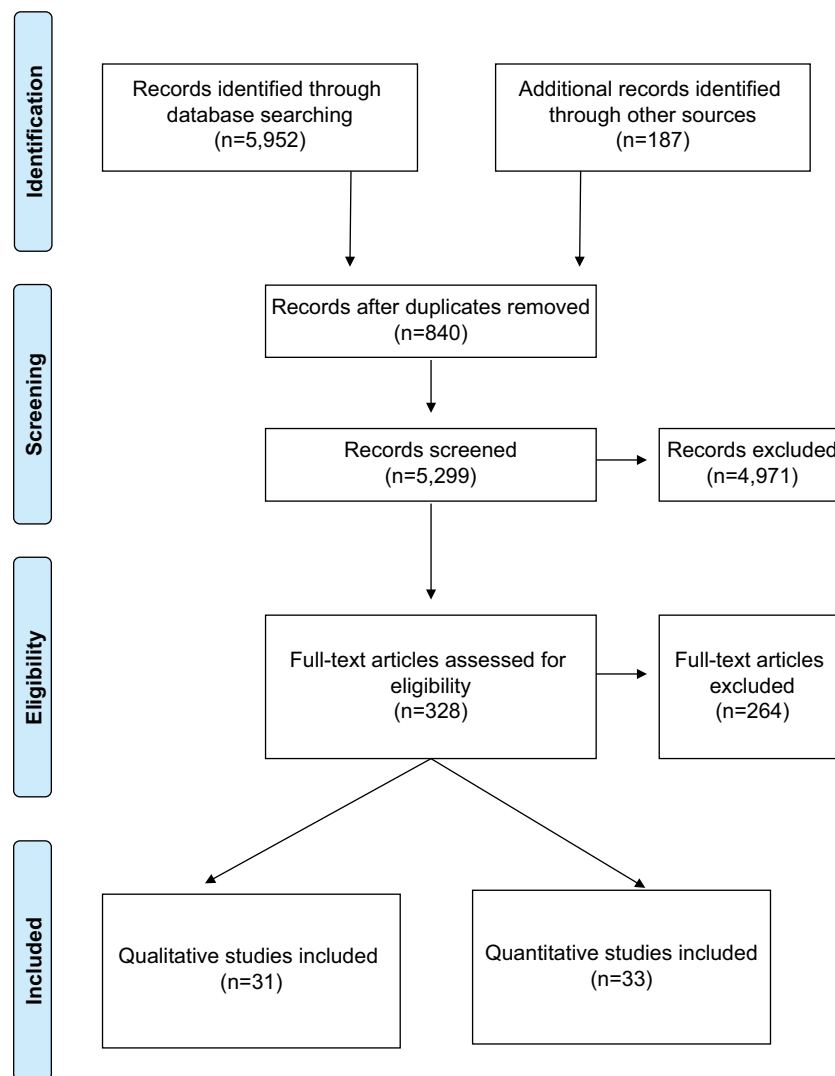


Figure 1 PRISMA flow diagram.

Table 1 Summary of characteristics of included qualitative publications related to treatment seeking

Study	Country	Participants	Design	Topic probed	Analytic approach	Relevant results
Ayres et al ⁵⁷	UK	n=20 Age: 55–66 years Sex: 85% male	Cross-sectional interviews In OST AND using illegal substances	Barriers to seeking treatment beyond OST	Inductive thematic analysis	Shame and embarrassment over drug use were reported by 70% of the sample, and 40% reported anticipating stigma from health care professionals. These feelings were strongly influenced by views of age-appropriate behaviors; participants felt ashamed and embarrassed for using drugs at their age. Indeed, 25% felt that age itself was a barrier, and 55% cited not wanting to be around younger drug users as the main reason they did not seek further help.
Bobrova et al ⁵⁶	Russia	n=86 Age: 16–44 years Sex: 81.4% male	Cross-sectional semistructured interviews People who inject drugs	Access to treatment services	Framework approach with two coding levels	Fear of registration as a drug user was identified as one of three major barriers to treatment by 90% of the sample. Registration was seen as a lifelong “stamp on the forehead” associated with loss of employment, confidentiality breaches, and stigma. Females felt doubly stigmatized by their sex and drug use.
Bojko et al ⁷⁵	Ukraine	n=41 Age: mean 35 years Sex: 88% male	Cross-sectional semistructured focus groups People who inject drugs and have no history of OST	Barriers to OST access and entry	Grounded-theory inductive approach with a constant comparative analysis method	Those who were unable to enroll cited bureaucratic barriers. Those who did not want to enroll reported associating enrollment with restrictions (on jobs and driver’s licenses) and stigma from police and society, who both view drug users as violent criminals.
Browne et al ⁶⁸	USA	n=40 Age: mean 34 years Sex: 80% female Race/ethnicity: 68% white, 30% African-American	Cross-sectional focus-group interviews In substance-abuse treatment	Perceived barriers to using a substance-abuse agency	Two-cycle coding analyzed with MaxQDA software	Participants identified stigma as a barrier to treatment. Diminished privacy due to small populations in rural areas contributed to perceived stigma. Racial stigma compounded this issue.
Conner and Rosen ⁶⁷	USA	n=24 Age: 50+ years Sex: 58% female Race/ethnicity: 58% African-American	Cross-sectional semistructured interviews In methadone maintenance treatment	Attitudes toward substance-abuse treatment Experiences with methadone maintenance treatment and drug addiction	Content analysis with inductive identification of themes and patterns	Stigma came from many sources (ie, family and friends, health care and drug-treatment staff, society). Drug-user stigma was the most common. Men reported more stigma than women. Perceived stigma of being an older drug user caused several participants to delay seeking methadone treatment.
Copeland ⁶	Australia	n=32 Age: 21–77 years Sex: 100% female Race/ethnicity: 94% Anglo-Saxon heritage	Cross-sectional structured interviews No history of substance-abuse treatment, but recovered	Stigma	Not discussed	Stigma was one of the principal barriers to treatment seeking: 78% of women felt they were more stigmatized for being substance users than men. These women avoided treatment to prevent themselves and their families from experiencing stigma. They often did not disclose use to primary-care doctors, even when it was medically relevant.

Dyson ³¹	UK	n=8	Cross-sectional narrative-method interviews In AA	Journey through recovery	Grounded-theory approach and content analysis	All participants made prior attempts to quit before achieving recovery. They reported behaviors to hide alcohol use, even from people they did not know well. Participants felt unable to seek help, due to this need for secrecy and stigma from health care providers, especially in emergency departments.
Freeman-McGuire ⁷⁷	USA	n=41 Age: 26–60 years Sex: 81% female Race/ethnicity: 63% Caucasian	Cross-sectional focus groups Nurses in recovery from substance abuse	Barriers to seeking treatment	Long-table approach to content analysis	Nurses reported perceived social stigma (especially from fellow nurses) as a barrier to seeking treatment. In contrast, such factors as shame, guilt, and social support helped them enter treatment. Once in recovery, they reported seeking to avoid shame and pain as reasons to maintain sobriety.
Gibbs et al ⁷⁸	USA	n=214 Age: 18+ years	Cross-sectional focus groups Army soldiers in treatment for substances (80) or not in treatment (134)	Barriers to accessing alcohol-abuse treatment	Content analysis of coded data using NVivo 8 software	Alcohol abuse was stigmatized mainly due to its association with problem behaviors, ie, soldiers were mandated to treatment after an incident, such as drunk driving, only. Thus, treatment was mostly punitive, and being treated associated with being unable to handle oneself and often one's job responsibilities.
Gilchrist et al ³⁴	Eight European countries	n=246 Age: 16–68 years Sex: 60%–84% male	Cross-sectional semistructured interviews and focus groups In treatment for alcohol or drugs	Service users' experiences of accessing alcohol and drug treatment and perceptions of staff	Thematic analysis with predetermined and inductive codes	Participants reported that fear of being called an "addict" and negative social attitudes led them to delay getting treatment. They also reported significant stigma against addicts from general health-service staff and that this was a barrier to treatment, whereas nonjudgmental staff were facilitators of treatment.
Gourlay et al ⁶	Australia	n=10 Age: 25–42 years Sex: 50% male	Cross-sectional interviews In a community-based methadone-treatment program	Experiences of methadone treatment	Modified grounded-theory analysis	Participants' experience of methadone-related stigma varied depending upon their self-concept. Those with conflicted self-concepts viewed methadone as a stigmatizing and disempowering intervention, while those with functional and nonaddict self-concepts found methadone beneficial and nonstigmatizing.
Gueta ³⁷	Israel	n=25 Age: 22–46 years Sex: 100% female Race/ethnicity: 52% Mizrahim	Cross-sectional interviews Mothers formerly or currently in a therapeutic community for substance abuse	Barriers to enrollment in drug treatment	Theoretical thematic analysis	96% of the sample had a history of failed therapy attempts. The role of stigma in treatment seeking was mixed, depending upon the attitudes of close friends and family. A family's fear of stigma could be a barrier to treatment, whereas the stigma of not getting treated could motivate treatment seeking. Overall, other factors, like poverty, were more influential.
Gunn and Guarino ⁷⁰	USA	n=26 Age: 18–29 years Sex: 69% male	Cross-sectional semistructured interviews Adult immigrants from Russia using or in treatment for opioids	Attitudes toward and use of drug-treatment and harm-reduction services	Content-based thematic analysis with deductive and inductive coding using Atlas.ti software	Stigma was felt from their communities, families, and the self. Drug use was seen as a moral weakness, particularly in women. This stigma kept users from seeking treatment. Alcohol abuse was not similarly stigmatized unless it impacted ability to function.

(Continued)

Table 1 (Continued)

Study	Country	Participants	Design	Topic probed	Analytic approach	Relevant results
Haighton et al ²⁹	UK	n=51 Age: 50–95 years Sex: 65% female	Cross-sectional interviews and focus groups Current or recovering dependent drinkers and people with drinking experience	Perceived social stigma	Grounded approach with NVivo 10 software	Dependent drinkers reported that they delayed seeking help in part because they felt strong stigma. Seeking help involved overcoming discomfort and embarrassment over admitting to the problem.
Jackson and Shannon ⁵⁴	USA	n=85 Age: mean 25 years Sex: 100% female Race/ethnicity: 97% Caucasian	Cross-sectional interviews Rural pregnant women in inpatient detoxification for drug dependence (subset of Jackson and Shannon) ⁵⁵	Treatment barriers	Three open-ended questions	Reported treatment barriers were coded into categories. The acceptability category included stigma barriers. 51% of responses fell into the acceptability category, but only 15% were specifically about stigma.
Jakobsson et al ²⁶	Sweden	n=12 Age: 20–69 years Sex: 58% male	Cross-sectional interviews In alcohol treatment	Factors that hinder treatment seeking	Content analysis by sex	Women and men both cited shame as a barrier to treatment. For women, this was accompanied by guilt, while for men it was accompanied by embarrassment.
Jones et al ⁷⁴	USA	n=29 Age: mean 37 years Sex: 100% female Race/ethnicity: 100% African-American	Cross-sectional focus groups In mental health or substance-use-disorder treatment	Experiences in substance-abuse treatment services	Grounded-theory approach with open and axial coding	Participants reported feelings of alienation and shame as a result of having a substance-use disorder and seeking treatment, and cited bias/stigma as a powerful reason not to do so. These issues were compounded by stigma associated with being black and being a woman, which brought judgment from providers and peers.
Khadjesari et al ³⁵	UK	n=18 Age: 25–67 years Sex: 56% women Race/ethnicity: 89% white British	Cross-sectional semistructured interviews Sought help for problem drinking online and agreed to participate in an intervention	Advantages and disadvantages of seeking help on the Internet	Thematic analysis using Atlas.ti 6 software	Seeking professional help was associated with shame and embarrassment. Many wanted to moderate drinking rather than abstain completely, and thus felt that programs like AA were stigmatizing because they catered to people labeled “alcoholics”. This was a reason not to participate in such programs.
Kozloff et al ³²	Canada	n=23 Age: 18–26 years Sex: 87% male Race/ethnicity: 61% white, 17% Asian	Cross-sectional focus groups Homeless and with a co-occurring disorder receiving mental health services	Barriers to service initiation for people with co-occurring disorders	Thematic content analysis	Being an “addict” was associated with being dirty and making poor choices, thus being labeled an “addict” by health care providers increased feelings of stigma. Psychiatric hospitalization invoked feelings of shame and fear, while provider and peer support was helpful in offsetting stigma.
Lembke and Zhang ⁷⁶	China	n=9 Age: 30–49 years Sex: 67% male	Cross-sectional interviews Heroin users seeking voluntary treatment at a private facility	Reasons for choosing treatment at the private facility instead of government facilities	Grounded-theory approach	All participants expressed experiences of severe stigma against people addicted to drugs and thus wanted treatment that was anonymous/confidential. The government system involved registration that followed one for life, and was thus mistrusted and avoided.

McCann et al ³⁸	Australia	n=28 Age: 16–25 years Sex: 64% male	Cross-sectional semistructured interviews with African migrants with personal experiences of substance-use problems in the community	What factors impede young persons from seeking help for substance abuse	Thematic analysis with inductive coding	Seeking formal help for drug or alcohol problems was viewed as a weakness/failure and avoided to prevent bringing shame on the family. In contrast, informal help from friends and family was seen as acceptable and desirable. Supportive friends and family could encourage formal service use.
Naughton et al ³⁹	UK	n=19 Age: 25–67 years Sex: 74% male Race/ethnicity: 100% white British	Cross-sectional semistructured interviews with Problem drinkers with varying levels of treatment experience	Influences on, reasons for, and experiences of seeking help for alcohol use	Thematic analysis using NVivo 7 software	Shame and stigma were cited by most as barriers to seeking help, often literally (eg, not attending a meeting in case someone you know sees you). 42% had sought only the lowest levels of help (ie, unstructured services like AA). Some reported that stigma and shame drove them to drink more, though one said they motivated him to seek treatment.
Neale et al ³⁰	UK	n=75 Age: 19–48 years Sex: 69% male	Cross-sectional semistructured interviews People who inject drugs and utilize a needle-exchange program	Problems experienced accessing drug-treatment services and reasons for not seeking support	Framework analysis, used MaxQDA 2 software	Most reported no barriers to accessing general practitioner care, but of those who did have issues, it was common to cite staff reacting to injector status with hostility and judgment. Stigma from pharmacy, hospital, and public housing staff was also reported. Some reported not wanting to access psychiatric care because getting that care was socially stigmatized.
Notley et al ³³	UK	n=43 Age: 18–45 years Sex: 72% male	Cross-sectional interviews and focus groups Problem drug users not currently in treatment	Barriers to accessing drug services	Thematic analysis, used NVivo software	Stigma was reported at various levels of social interaction, from one-to-one settings to within small social groups to society at large. Stigma led to problems accessing services when the location of the service was somewhere one was likely to see people one knew, especially in tight-knit communities.
Otiashvili et al ⁷¹	Georgia	n=55 Age: 18–55 years Sex: 100% female Race/ethnicity: 95% Georgian	Cross-sectional semistructured interviews Women who inject drugs	Substance-abuse treatment needs and experiences	Parallel content and thematic analysis with a priori and inductive categories and subcategories using NVivo 9 software	Substance abuse was seen as a serious deviation from the female norm, such that women labeled themselves as morally weak, irresponsible, and negligent for being users. This self-stigma was a significant barrier to disclosure of use. Women also reported health care-provider stigma as a barrier to treatment seeking.
Radcliffe and Stevens ¹⁷	UK	n=53 Age: 19–50 years Sex: 74% male Race/ethnicity: 75% white British	Cross-sectional interviews Problematic drug users who dropped out of treatment services	Stigmatization of drug users and drug services	Adaptive coding using NVivo software	Participants attempted to maintain self-esteem by placing themselves morally above other drug users, but accessing treatment made this separation more difficult, and thus they felt treatment access was stigmatizing and to be avoided. Stigma was also a strong factor in their decision to leave treatment.
Sexton et al ⁴⁶	USA	n=86 Age: 18–55 years Sex: 60% male Race/ethnicity: 59% white, 40% African-American	Cross-sectional interviews Illicit-stimulant users	Barriers that impede entering treatment programs	Transcripts were coded and analyzed manually to identify themes and patterns	Only 43% of participants had previously entered drug-abuse treatment. A few participants reported social stigma as a barrier to seeking treatment, but overall most simply did not feel they needed help. Indeed, only 19% of the sample felt they had a current need for treatment, and 8% were ambivalent.

(Continued)

Table 1 (Continued)

Study	Country	Participants	Design	Topic probed	Analytic approach	Relevant results
Smye et al ⁶⁹	Canada	n=39 Age: 19+ years Sex: 49% male Race/ethnicity: 100% Aboriginal	Cross-sectional interviews and focus groups Aboriginal persons in methadone maintenance therapy	Experiences of seeking care	Interpretive thematic analysis using NVivo software	Perceived health care-provider stigma was a barrier to accessing methadone maintenance, but this stigma interacted with others (eg, racial, socioeconomic), such that participants were not always certain behavior was directly attributable to drug-user stigma.
van Olphen et al ⁷²	USA	n=17 Age: 22–53 years Sex: 100% female Race/ethnicity: 59% African-American	Cross-sectional semistructured interviews and focus groups Female drug users released from jail	Challenges finding drug treatment	Thematic analysis	Most women felt that stigma kept them from accessing appropriate treatment services. Services in the jail were viewed as insufficient and stigmatizing, and most women resumed drug use after their release.
Finn et al ⁷⁷	Sweden	n=32 Age: 18–62 years Sex: 56% male	Cross-sectional semistructured interviews and focus groups People with alcohol dependence	Reasons for seeking and not seeking treatment	Thematic analysis	Participants in focus groups and interviews described a need for treatment as a shameful failure and expressed a desire to keep their alcohol dependence a secret from others.
Wieczorek ²⁸	Poland	n=50	Cross-sectional interviews People with alcohol dependence who had begun treatment	Difficulties with seeking and receiving help	Manual coding and categorization	Participants had been reluctant to seek treatment because they felt ashamed and humiliated by their need, which was revealed by going to the treatment facilities. Rural patients were especially concerned.

Abbreviations: AA, Alcoholics Anonymous; OST, opioid-substitution therapy.

Table 2 Summary of characteristics of included quantitative publications related to treatment seeking

Study	Country	Participants	Design	Relevant constructs	Construct measurements	Relevant results
National Survey on Drug Use and Health Studies (NSDUH) data						
Ali et al ¹⁰	USA	n=1,300 Age: 18–64 years Sex: 67% male Race/ethnicity: 62% white, 17% black, 15% Hispanic	Years 2008–2013 Those who felt an unmet need for SUD treatment	Treatment barriers	List of 13 reasons not to get treatment	Overall, 10% of participants reported stigma as a reason not to get treatment, but this differed by insurance status. Privately insured individuals were six times likelier than people on Medicaid to report stigma as a barrier. The biggest barrier for the privately insured was a lack of readiness to stop using, whereas for those on Medicaid access, barriers were primary.
Chen et al ¹¹	USA	n=1,259 Age: 18+ years Sex: 57% male Race/ethnicity: 67% white, 10% black, 14% Hispanic	Years 2005–2010 Those who felt an unmet need for SUD treatment	Treatment barriers	List of 13 reasons not to get treatment	“Stigma reasons” were reported by about 23% of all participants (the least frequent of four barrier categories). Reasons within this category did not vary significantly by group, but numerically men with comorbid depressive episodes were more concerned about neighbors’ opinions than men with just SUDs, while women with comorbid depressive episodes were less concerned about negative job effects than men with this comorbidity.
Choi et al ¹²	USA	n=96,966 Age: 26+ years Sex: 52% female Race/ethnicity: 69% white, 11% black, 13% Hispanic	Years 2008–2012 Those over the age of 26 years	Treatment barriers	List of 13 reasons not to get treatment	Of those with SUDs not seeking treatment, 21% cited stigma concerns. Adults aged >65 years were least likely to be concerned with stigma (12%), whereas adults aged between 26 and 34 years were the most likely to report this concern (25%); however, this difference was not statistically significant.
Mojtabai et al ¹³	USA	n=393 Age: 18–25 years Sex: 56% female Race/ethnicity: 67% non-Hispanic white	Years 2005–2011 Those who felt an unmet need for SUD and MH treatment	Treatment barriers	List of 13 reasons not to get treatment	The top four reasons for not seeking SUD treatment were: cannot afford it (43%), do not want to stop using (39%), fears of social stigma (23%), and lack of knowledge of options (18%). Less frequent concerns were treatment having a negative effect on a job (15%) and not wanting others to find out (10%).
Wu et al ¹²	USA	n=1,788 Age: 12–17 years	Years 2005–2008 Adolescents with opioid abuse or dependence	Treatment barriers	Structured questions	89 adolescents perceived a need for treatment. Of these, only 13% had used services in the past year. The top reasons these individuals reported for not seeking treatment were: not ready to stop (34%), did not want others to find out (22%), and treatment might be seen negatively by neighbors (22%).
National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) data						
Allen and Mowbray ⁴⁴	USA	n=11,182 Age: 18+ years Sex: 67% male Race/ethnicity: 79% white	Wave 1 and wave 2 Lifetime diagnosis of AUD	Treatment barriers	List of 26 reasons not to get treatment	10% of the sample perceived unmet need for treatment for alcohol abuse. Bisexual individuals were more likely than heterosexuals and gay or lesbian individuals to report being too embarrassed to discuss their use with anyone, and were more fearful of what others would think than heterosexuals were.

(Continued)

Table 2 (Continued)

Study	Country	Participants	Design	Relevant constructs	Construct measurements	Relevant results
Cohen et al ¹⁴	USA	n=11,748 Age: mean 42 years (SD 15) Sex: 67% male Race/ethnicity: 80% white	Wave 1 Lifetime diagnosis of AUD	Treatment barriers	List of 27 reasons not to get treatment	4% of the sample reported unmet need for treatment. The most frequent reason for not seeking help was the belief they should be strong enough to handle it alone, while being embarrassed to discuss it was the fifth-most frequent. People who thought about treatment were less educated and had more comorbidities than those who had never thought about it.
Keyes et al ¹⁵	USA	n=6,309 Age: 20+ years	Wave 2 Lifetime diagnosis of AUD and completed the stigma measure	Alcohol-related stigma	Perceived Devaluation-Discrimination Scale	Treatment-utilization rates were 24% with low stigma, 21% with high stigma, 18% with middle-high stigma, and 17% with middle-low stigma. Adjusting for disorder severity, the odds of getting help decreased with increases in stigma.
Mojtabai and Crum ¹³	USA	n=195 Age: 18+ years Sex: 70% male	Wave 1 and wave 2 Untreated for SUD in past 12 months, perceived need for treatment	Treatment barriers	List of 27 reasons not to get treatment	Overall, 15% of the sample had sought treatment by wave 2. Stigma was the second-most frequent barrier reported at baseline: 59 participants (30%) reported it. Of these, 14% had sought treatment at wave 2. The most frequently reported barrier was self-reliance/problem minimization (n=145; 74%): 16% of those who reported this barrier sought treatment by wave 2. In regression analysis, stigma was not a significant predictor of treatment seeking. The barrier of treatment pessimism was the only significant predictor.
Schuler et al ¹⁵	USA	n=1,053 Age: mean 44 years Sex: 68% male Race/ethnicity: 76% non-Hispanic white	Wave 1 Lifetime AUD, with perceived need for treatment, but treatment-naïve	Treatment barriers	15 items from a list of 26 reasons not to get treatment	Latent class-regression analysis showed that there were two groups of untreated individuals: 87% fell into the low-barrier category and had mainly attitudinal treatment barriers. The remaining 13% were high-barrier individuals and had attitudinal, financial, stigma, and readiness-for-change barriers. 62% of the higher-barrier group said they were "too embarrassed to discuss it with anyone" (third-most frequent answer out of 15) and 45% were "afraid of what [others] would think" (seventh). In contrast, only 12% (fourth) and 3% (eleventh) of the low-barrier group endorsed these items, respectively.
Smith et al ¹⁹	USA	n=4,857 Age: 18+ years Race/ethnicity: 71% white, 11% black, 12% Hispanic	Wave 1 and wave 2 Lifetime AUD	Alcohol-related stigma	Perceived Devaluation-Discrimination Scale	Stigma varied by race and ethnicity, with the lowest levels in whites and Native Americans. Only 24% of those with lifetime AUD had sought treatment. Race/ethnicity was not a predictor of treatment utilization, not even when considering stigma in the statistical model.
Other longitudinal studies						
Fortney et al ⁶⁰	USA	n=170 Age: 18–60 years Sex: 58% male Race/ethnicity: 78% African-American	Interview ER patients with chest pain and cocaine use	Treatment barriers	Substance Abuse Outcomes Module, which includes four items related to stigma barriers	At 3-month follow-up, 25% of the sample had sought some form of treatment. Stigma positively and significantly predicted treatment use at follow-up: for every additional stigma barrier, the odds of treatment increased by 4.4. Other treatment barriers did not predict treatment.

Grant ⁸	USA	n=964 Age: 18+ years Sex: 64% male Race/ethnicity: 90% nonblack	NLAES Those who felt an unmet need for AUD treatment	Treatment barriers	List of 21 reasons not to seek treatment Open-ended reasons from participants	"I should be strong enough to handle it alone" was the most frequently endorsed barrier at 29%. "Too embarrassed to discuss with anyone" was reported by 11%, and 8% said they were "afraid of what others would think". Only 2% were "afraid of losing job", and 0.5% said a "family member objected". African-Americans endorsed these more frequently, but only "afraid of what others would think" was significantly higher.	
Hingson et al ⁴⁷	USA	n=231 Age: 18–65 years	Interview and survey Lifetime problem with drinking	Reasons for not seeking treatment	Likert-rated items	21% said they considered getting help, but only 15% did. 84% of those who did not seek help said their problem was not serious, and 96% said they could handle it themselves. 26% said they worried what others would think, but 56% said they did not want to admit they needed help.	
Semple et al ⁶⁶	USA	n=292 Age: mean 38 years Sex: 72% male Race/ethnicity: 55% Caucasian	Computer-assisted interview Methamphetamine users in a risky sexual behavior-reduction program	Stigma	Expectation of rejection, experience of rejection, stigma-coping strategies	Endorsement of items on all three stigma scales was high (58%–96%). Treatment and nontreatment groups expected rejection equally, but previous experience in treatment was related to more actual experiences of rejection. Those never in treatment endorsed more stigma coping. Regression analysis suggested that experiences of rejection and stigma-coping strategies best discriminated between treatment seekers and treatment nonseekers.	
Zemore et al ⁵⁰	USA	n=555 Sex: 52% female Race/ethnicity: 100% Hispanic	NAS years 1995, 2000, and 2005 Lifetime AUD, treatment-naïve	Treatment barriers	List of seven reasons not to seek treatment	5.5% said they did not seek treatment because they were too afraid of people finding out. Endorsement was higher among men (6.3%) than women (3.3%) and among Spanish speakers (7.9%) than English speakers (3.5%).	
Cross-sectional studies							
Allen and Mowbray ⁴⁴	USA	n=97 Age: 18+ years Sex: 100% female Race/ethnicity: 64% African-American, 30% white	Survey Women abusing substances and not in treatment	Treatment barriers	Allen Barriers to Treatment Instrument	The top three barriers to treatment were role responsibilities, lack of money, and lack of insurance. The sixth-most frequently reported barrier was shame felt when admitting to addiction. This barrier was reported by 40% of the sample. Overall, the women in the sample reported more personal/internal barriers to treatment than external barriers.	
Calabrese et al ⁶¹	Russia	n=383 Age: 20–51 years Sex: 79% male	Survey Injecting drug users with HIV	Internalized drug stigma	Six-item Internalized AIDS-Related Stigma Scale, adjusted for drug-user status	There was a small correlation between higher internalized drug stigma and not getting treatment in the past year. In regression analysis, there was no main effect of drug stigma on drug-treatment utilization; however, there was a significant interaction in that people with both high drug stigma and high HIV stigma were less likely to get drug treatment.	
Cares et al ⁴¹	USA	n=256 (of 302) Age: 18+ years Sex: 81% female	Survey Nurses with alcohol and drug issues	Barriers to seeking assistance	Likert survey items for barriers to seeking assistance	63% of the sample said they were too scared to seek help, while 61% said they were embarrassed and 56% said they were concerned about confidentiality. The scared and confidentiality items may relate more to a fear of losing a job than stigma per se.	

(Continued)

Table 2 (Continued)

Study	Country	Participants	Design	Relevant constructs	Construct measurements	Relevant results
Cellucci et al ⁶²	USA	n=133 Age: mean 23 years Sex: 56% female Race/ethnicity: 86% Caucasian	Survey Psychology students who consumed alcohol	Stigma Help-seeking interest	Stigma measure Help-seeking interest scale	In a regression analysis to predict help-seeking interest, the biggest predictor was problem recognition. Stigma was also a significant (negative) predictor in this model. A second regression analysis to predict problem recognition showed that AUDIT scores were the biggest predictor. Stigma was also a significant (positive) predictor.
Cunningham et al ⁷	Canada	n=346 Age: mean ~38 years (SD ~10) Sex: 79% male	Survey and structured interview People with SUD who delayed or had never had treatment	Treatment barriers	List of five factors in delaying/not seeking treatment, rated by degree of influence Open-ended reasons from participants, coded into eleven categories	Analysis 1: Drug users vs alcohol users: Stigma was the second-most frequent barrier reported by drug users, and tied for first in alcohol users. However, it was not in the top five (of eleven) most influential reasons for either. Analysis 2: Three groups of alcohol users: Regarding stigma, outpatients reported it more frequently but as being less influential in their decision to delay treatment than both untreated groups (self-resolved and unresolved). Stigma was most influential for the untreated unresolved group; this group also reported embarrassment/pride most frequently, though the untreated self-resolved group rated embarrassment/pride as more influential.
Gates et al ⁵¹	Australia	n=494 (100 in treatment, 100 not, 294 online) cannabis users Age: range 16–89 years Sex: 58% male	Interviews and Internet survey Individuals in treatment or using cannabis weekly	Treatment barriers	Grounded-theory approach with open coding of interview and Internet-survey responses	12% of the sample reported stigma as a barrier to treatment. Reports varied significantly by group, with 22% of those not in treatment, 13% in treatment, and 8% of Internet participants citing stigma. They also found that the odds of reporting stigma as a barrier increased as the reported number of days per week of cannabis use increased.
Green ²	USA and global	n=218 Age: 18+ years Sex: 71% female Race/ethnicity: 76% Caucasian, 10% Asian/Pacific Islander	Internet survey Users worried about alcohol use	Treatment barriers	Barriers questionnaire rating the importance (0–3) of 56 potential barriers	Stigma was endorsed by 60% of the sample. The mean importance rating for stigma was the third highest of 9. 14% were currently in treatment, and 11% were considering it. Regression analysis did not support a relationship between perceived barriers (ie, a sum of all barriers) and a history of treatment use, but individual barriers were not assessed.
Jackson and Shannon ⁵⁵	USA	n=114 Age: mean 25 years Sex: 100% female Race/ethnicity: about 95% Caucasian	Mixed methods: open-ended items and treatment-motivation scale Pregnant women in inpatient drug detoxification	Barriers to entering the detoxification program Treatment motivation	Reported barriers were coded into four predetermined categories using NVivo 9 software	15% of rural and 21% of urban women reported stigma as a barrier. Stigma fell under the category of acceptability (of treatment). This category was a significant predictor of increased treatment motivation, as measured by the Treatment Attitude Profile Scale.

Myers et al ⁶⁴ and Myers ⁶³	South Africa	n=989 Age: mean 25 years Sex: 52% male Race/ethnicity: 51% black/African, 49% mixed race	Interview with ATQ People from disadvantaged communities with AOD problems, seeking treatment or not	Internalized stigma Factors restricting treatment use	Stigma Consciousness Scale Items on the ATQ	Male and female cases scored significantly higher on stigma consciousness than male and female controls. Stigma consciousness was related to treatment utilization only in women, however (OR 3.14, 95% CI 1.89–5.20). For both racial groups, treatment seekers scored significantly higher on the stigma scale than treatment nonseekers. Scores on the stigma scale were significantly correlated with treatment utilization for both black Africans ($r_{pb} = 0.33$) and “colored” participants ($r_{pb} = 0.25$). Regression analyses showed that a 1-U increase in stigma scores doubled the odds of accessing treatment services for “colored” participants only.
Pal et al ⁴⁹	India	n=79 Age: mean 38 years Sex: 100% male	Semistructured interview AUDIT score ≥ 8 , treatment-naive	Treatment barriers	Asked to state reasons for not seeking care, with seven choices	51% thought their drinking was a social issue, while 14% thought it was a moral one, and 3% thought it was medical. The most frequent barrier to seeking help at the nearby clinic (22%) or any other clinic (27%) was shame in admitting a problem. The sixth-most frequent barrier was being “afraid of label” (11% and 4% for nearby and other clinics).
Probst et al ³⁹	Italy, Germany, Hungary, Latvia, Poland, and Spain	Past 12 months: n=251 Lifetime: n=664 Age: 18–64 years	Semistructured interview Individuals with untreated AUD	Treatment barriers	Open-ended items for past 12 months and lifetime Set of closed questions for past 12 months only	Past 12 months: The most common reason for not seeking treatment was “lack of problem awareness” (55%), followed by “stigma or shame” (28.6%). “Cope alone” was endorsed by 21%. Lifetime: The top two reasons were “lack of problem awareness” (78%) and “cope alone” (17%). Less than 5% of respondents endorsed other reasons, with only 2% endorsing “stigma and shame”. Shame and stigma were more common in Spain than in the other countries. Individuals with subthreshold or mild AUD more often cited denial of a problem, whereas those with moderate or severe AUD reported more barriers to treatment.
Saunders et al ⁶⁵	USA	n=145 Age: mean 44 years Sex: 70% male Race/ethnicity: 76% Caucasian	Structured interview AUDIT score ≥ 8 , admitted need for treatment, in treatment or not	Treatment barriers	21 barriers to treatment	Those not seeking treatment more often thought they should handle it on their own. Other person-related barriers relevant to stigma (eg, feeling embarrassed about the problem) did not differ between those seeking treatment and not. Regression analysis showed that sex, education, and person-related barriers (ie, stigma-related barriers plus additional items) all significantly predicted membership in the nonseeker or seeker group.
Small et al ⁷³	USA	n=733 Age: mean 32 years Sex: 67% male	Interview At-risk drinkers in southern states	AUD stigma	Response to a vignette about a person with AUD	Women reported lower levels of stoicism and greater community stigma for consuming alcohol than men. However, there was no difference between men and women in help seeking in the past 6 months nor in receiving a diagnosis of AUD.
Stepanyan ⁶⁰	USA	n=100 Age: 13+ years Sex: 50% female	Structured interview Methamphetamine users in treatment	Stigma	One Likert-rated item	All agreed that family and society influenced them to seek treatment. 60% of females and 92% of males agreed that stigma had previously prevented them from getting treatment.

(Continued)

Table 2 (Continued)

Study	Country	Participants	Design	Relevant constructs	Construct measurements	Relevant results
Tucker et al ⁴³	USA	n=39 Age: mean 45 years Sex: 77% male Race/ethnicity: 69% Caucasian	Interview Active or abstinent problem drinkers never in treatment	Treatment barriers	Five reasons not to seek treatment, rated for influence from 1 to 5	The most frequently reported barriers were "potential embarrassment" (66%, mean influence 2.6) and "concerns about the stigma or label of alcoholic" (63%, mean influence 2.7). Abstinent individuals rated barriers as marginally more influential than current drinkers did. Treatment cost was significantly less of a barrier than the other four reasons provided.
van der Pol et al ⁴⁸	Netherlands	n=241 Age: mean 24 years Sex: 61% male	Structured interview Cannabis-dependent individuals not seeking treatment	Treatment barriers	Open-ended item and 11 reasons not to seek treatment	30 people had subjective need for treatment, but were not seeking it. 13% of these individuals cited "avoiding stigma" as a reason not to seek treatment. 63 people had objective need for treatment, but were not seeking it. 8% of these individuals cited "avoiding stigma" as a reason not to seek treatment.

Note: Specific questions abbreviated used in lieu of an actual scale.

Abbreviations: AUD, alcohol-use disorder; AOD, alcohol and other drug; ATQ, Access to Treatment Questionnaire; MH, mental health; NILAES, National Longitudinal Alcohol Epidemiology Survey; SUD, substance-use disorder.

or not such stigma was objectively present. Also of note, the etiology of reports of stigma from health care professionals could be debated as a version of structural stigma, the process of institutions having a culture of stigmatizing policies and practices (with employees representing the policies and attitudes of the places in which they work), or public stigma (with their attitudes representing their own core beliefs). We chose to interpret it as the latter, and instances of this are noted as perceived health care-professional stigma, a subset of perceived social stigma, in the tables. Not all studies used the exact constructs of self-stigma or perceived social stigma in their work. However, the constructs we included were those that were most closely related to these types of stigma and measured some aspect of one or the other.

Qualitative stigma experiences

A number of qualitative studies (see Table 1) have provided an overview of the stigma experiences of those in need of treatment for substance abuse. Feelings of shame,^{26–28} embarrassment,^{26,29,30} and guilt²⁶ were reported. Problem substance users also reported a need for secrecy about both their use and any attempts to seek treatment.^{27,28,31} This secrecy was linked to perceptions of stigma from health care providers in general practice and emergency settings, who may be the first source of help available, and thus the need for secrecy was said to lead to delays in treatment seeking.^{29–33} Two studies suggested that these feelings and need for secrecy stemmed from a strong desire to avoid accepting the identity of "addict" or "junkie",^{34,35} while two more found that even those who had attempted to seek treatment may disengage when identity conflicts arise.^{17,36} On the other hand, participants in one study said they had sought help from a general practitioner specifically to avoid stigma from social sources,³³ while those in other studies said that emotional support from loved ones had facilitated seeking formal help for substance abuse.^{37,38}

Frequency of stigma as a barrier

Of the 33 quantitative studies summarized in Table 2, 23 shed light on the frequency with which stigma was perceived as a barrier to treatment relative to other barriers. Stigma-as-barrier frequencies ranged from just 2%³⁹ up to 92%⁴⁰ (mean 30.39%, SD 19.46%). Using 50% frequency as a cutoff to differentiate between high ($\geq 50\%$) and low ($< 50\%$) stigma-frequency studies, only four^{40–43} fall into the high-frequency category (mean 67.00%, SD 11.37%). All these high-frequency studies were cross-sectional. Among the low-frequency studies (mean 31.33%, SD 19.99%), three reported high stigma frequencies in certain subsets of

their sample.^{7,44,45} Bisexuals (compared to heterosexual and homosexual,⁴⁴ but see also Green,⁴² who found heterosexuals reported stigma more often than homosexual and bisexual individuals), people with many barriers (compared to few barriers),⁴⁵ and alcohol users (compared to drug users)⁷ all reported stigma as a barrier >50% of the time, whereas their comparison groups did not. In a primarily qualitative study of illicit-stimulant users, less than half had entered drug-abuse treatment and most did not feel they needed help; social stigma was cited only by a few as a barrier to treatment.⁴⁶ The remaining 16 studies all reported low frequencies for stigma (mean 18.99, SD 8.59). These studies were both longitudinal (n=10) and cross-sectional (n=6).

Relative to other barriers, the frequencies reported in the 23 studies put stigma (or stigma-relevant constructs) in ordinal ranks ranging from most to 13th-most frequently reported (see Table 3). Overall, stigma (or a stigma-like construct) was in the top-three most frequent barriers in 17 studies. These studies also reported the frequencies of other treatment barriers. “Should handle alone” was the most frequent barrier in seven studies,^{8,13,14,44,45,47,48} stigma (or stigma-relevant constructs) in six studies,^{7,39–41,43,49} denial of a problem in five,^{13,39,42,50,51} “not ready to quit” in three,^{10,12,52} cost and access barriers in four,^{10–12,53} role responsibilities in two,^{44,54} and treatment attitudes in one.¹¹ Note that barriers tied for most frequent in several studies, and that the rank order of barriers often varied by participant group (eg, men vs women). See Table 3 for more details.

Only five qualitative articles in Table 1 reported frequency of stigma as a barrier, ranging from 15%⁵⁵ to 90%⁵⁶ (mean 55.75%, SD 29.90). The highest frequency was from a study where stigma was associated with a national drug-user registration system that led to lifelong consequences.⁵⁶ The second-highest frequency, 78% for female substance users, actually reflects the number of women who felt compounded stigma for being both female and a user.⁶ The remaining three frequencies were <50%,^{55,57,58} and one of these duplicates data from an article in Tables 2 and 3.^{54,55}

Degree of influence of stigma

In addition to frequency, three quantitative studies directly asked participants to rate the degree of influence stigma had on their decisions about treatment seeking. In the first, mean ratings (on a scale from 1 [not influential] to 5 [very influential]) were 3.7 for alcohol users and 3.4 for drug users.⁷ These values were the seventh- (for alcohol users) and eighth- (for drug users) highest influence ratings: the most influential barrier for alcohol users was being unaware of treatment options,

while for drug users it was being in denial of a problem. In the second study, the mean stigma-influence rating for alcohol users was 0.72 (on a scale from 0 [not influential] to 3 [very influential]), with stigma being the third-most influential barrier of nine.⁴² In this study, denial of a problem was the most influential barrier. Finally, the third study found that problem drinkers’ mean stigma-influence rating was 2.7 (on a scale from 1 [not influential] to 5 [very influential]), with stigma being the most influential of six barriers.⁴³

Stigma as a statistical predictor of treatment

Twelve studies that did not ask participants to rate directly the influence of stigma on their treatment-seeking decisions did use statistical methods to determine whether or not stigma predicted treatment motivation and/or utilization.^{13,15,42,54,59–66} Of these, five found stigma to be a positive predictor or copredictor,^{54,60,63–65} three found it to be a negative predictor or copredictor,^{15,61,62} and three found it not to be a predictor at all.^{13,42,59}

The first study that found stigma to be a positive predictor found that stigma barriers significantly predicted treatment utilization at 3-month follow-up for cocaine users seen in the emergency room, while other types of treatment barriers did not.⁶⁰ The second study found that pregnant women in a detoxification program who reported an acceptability barrier (a category that included stigma) had increased treatment-motivation scores, while gestational age of the fetus was a negative predictor.⁵⁴ The third and fourth studies were different analyses of the same data. The third study found stigma consciousness to be a positive predictor of current treatment utilization for women only,⁶⁴ while the fourth found it to be a significant positive predictor for “colored” participants only.⁶³ The final study found that person-related barriers (a category that included stigma, but also “wanting to handle the problem on your own” and not having motivation or reasons to stop drinking) positively predicted currently being in treatment. Sex and education level were also positive predictors, while intrapersonal consequences and emotional distress were negative predictors.⁶⁵

The first study that found stigma to be a negative predictor found that higher alcohol-related stigma (controlling for disorder severity, sex, age, race, ethnicity, income, education, and marital status) was related to less lifetime use of any treatment option.¹⁵ The second study found that drug stigma was related only to 12-month treatment utilization in those who also had high HIV stigma.⁶¹ The third study was conducted with psychology students, and found that more stigma was related to less interest in seeking help.⁶²

Table 3 Summary of barrier frequency rankings in articles with frequency data

Study	Barriers assessed	Stigma as item or in category	Stigma or stigma-like construct	Participant groups (if sample divided)	Stigma-construct rank	First barrier	Second barrier	Third barrier
Ali et al ¹⁰	5	Category	Stigma	Private insurance Medicaid	Second Fifth	Not ready to quit Access barriers	Stigma Not ready to quit	Not a priority Cost
Chen et al ¹¹	4	Category	Stigma	Men with depression Men, no depression Women with depression Women, no depression	Fourth Fourth Third Fourth	Cost Treatment attitudes Treatment attitudes	Cost Cost	Structural reasons Structural reasons Stigma
Choi et al ¹²	9	Item	Stigma	26–64 years old 65+ years old	Third Fourth	Cost/limited insurance Not ready to quit	Not ready to quit Unaware of options	Stigma/confidentiality Cost/limited insurance
Mojtabai et al ¹³	13	Item	Social stigma of treatment	NA	Third	Cost	Not ready to quit	Social stigma of treatment
Wu et al ¹⁴	14	Item	Secrecy and social stigma of treatment	NA	Second/third	Not ready to quit	Others find out	Social stigma of treatment
Allen and Mowbray ⁴⁴	26	Item	Embarrassment and social stigma of treatment	Heterosexual Gay or lesbian Bisexual	Fourth/thirteenth Fourth/ninth Fifth/ninth	Should handle alone Should handle alone Should handle alone	Problem resolve itself Not ready to quit Problem resolve itself	Problem not serious enough Problem not serious enough Problem not serious enough
Cohen et al ¹⁴ Mojtabai and Crum ¹³	10 6	Item Category	Embarrassment Stigma	NA NA	Fifth Second	Should handle alone Self-reliance/denial	Problem resolve itself Stigma/social consequences	Stopped on my own Structural reasons
Schuler et al ⁴⁵	15	Item	Embarrassment and social stigma of treatment	Low barriers	Third/seventh	Should handle alone	Problem resolve itself	Not ready to quit and did not believe problem
Grant ⁸	26	Item	Embarrassment and social stigma of treatment	High barriers Men Women	Fifth/eleventh Sixth/ninth Fourth/seventh	Should handle alone Should handle alone Should handle alone	Problem resolve itself Problem not serious enough Problem resolve itself	Embarrassment Problem resolve itself Problem not serious enough
Hingson et al ⁴⁷	7	Item	Social stigma of treatment	NA	Sixth	Should handle alone	Problem not serious enough	Did not want to admit problem
Zemore et al ⁵⁰	8	Item	Secrecy	NA	Fourth	Did not believe a problem	Thought no one understand	Unaware of options
Allen and Mowbray ⁴⁴	8	Item	Ashamed to admit	NA	Fifth	Role responsibilities	Cost	Limited insurance
Cares et al ⁴¹	9	Item	Scared and embarrassment	NA	First/second	Scared to seek help	Embarrassment	Secrecy
Cunningham et al ⁷	10	Item	Stigma	Alcohol users Drug users	First/second Second	Stigma and unable to share Unable to share	Stigma and unable to share Stigma	Embarrassment/pride Embarrassment/pride
Gates et al ⁵¹	15	Item	Treatment stigma	No treatment Cannabis treatment Internet survey	Second Fifth Fourth	Did not believe a problem Did not believe a problem Did not believe a problem	Treatment stigma and unaware of options Not ready to quit Not ready to quit	Treatment stigma and unaware of options Unaware of options and hard to admit Unaware of options

Green ¹²	9	Category	Stigma	NA	Fifth	Problem not serious enough	Lack of change motivation	Treatment attitudes
Jackson and Shannon ¹⁵	19	Item	Stigma	Rural women Urban women	Second Second	Role responsibilities Role responsibilities	Stigma and denial and process Stigma and process	Stigma and denial and process Stigma and process
Pal et al ¹⁹	7	Item	Ashamed to admit and afraid of label	Specific clinic	First/fourth	Ashamed to admit	Treatment pessimism	Social support needed
Probst et al ¹⁹	22	Item	Stigma or shame	Other clinic Past 12 months Lifetime	First/sixth First Ninth	Ashamed to admit Fear of stigma or shame Did not believe a problem	Treatment pessimism Problem not serious enough Problem not serious enough	Stopped on my own Did not believe a problem
Stepanyan ⁴⁰	4	Item	Stigma	NA	First	Stigma	Role responsibilities	Should handle alone
Tucker et al ⁴³	6	Item	Stigma or label and embarrassment	NA	Second	Embarrassment	Stigma or label of alcoholic	Medical conditions Unable to share
van der Pol et al ⁴⁸	8	Item	Stigma	Would not seek treatment Objective need for treatment Subjective need for treatment	Sixth Sixth Third	Should handle alone Should handle alone Should handle alone	Prefer informal help Problem not serious enough Treatment pessimism	Problem not serious enough Prefer informal help Stigma

Abbreviation: NA, not applicable/not available.

Finally, one study that did not find stigma to be a significant predictor found that alcohol-related stigma did not predict treatment seeking 1 year later.¹³ A second study found that alcohol-related stigma was related to race, but that race did not predict treatment seeking 1 year later.⁵⁹ The third study grouped stigma with all perceived barriers, and found it did not predict having a history of treatment use.⁴²

Compounding effects of multiple stigmas

A total of 29 studies reported on the combined effects of multiple stigmas on treatment-seeking decisions.^{6,8,11,12,30,37,39,41,44,45,50,55-57,59,61,63,64,67-78} Generally speaking, individuals with more barriers to treatment were found to be less likely to seek treatment than those with fewer barriers in one study.⁴⁵ More specifically, participants across various studies reported compounded effects on treatment decisions of being both substance users and older,^{57,67} a member of a racial or ethnic minority,^{8,50,59,64,68,69} HIV-positive,⁶¹ dually diagnosed with depression,¹¹ or female.^{6,30,37,50,54,56,64,70-74} Females in several studies had a number of additional stigmas, including that of being pregnant,⁵⁴ incarcerated,⁷² or black.⁷⁴ Stigmas were particularly influential on women when their substance use and/or usage of treatment services had implications for child-custody arrangements.^{30,37} Other institutional influences also increased the influence of stigma. Studies in countries with drug-user registries showed that fears of the consequences of the registration process affected decisions to seek treatment for many.^{50,56,75,76} Country of origin also impacted the influence of stigma in the absence of such programs, likely via social and cultural expectations.³⁹ Additionally, sexual orientation (bisexuality compared to homo- and heterosexuality)⁴⁴ and some chosen careers (nursing and army soldiers)^{41,77,78} increased the influence of stigma in some studies.

Congruently with these findings, a study that did not specifically measure multiple stigmas, but did look at the ability of demographic variables to predict treatment use longitudinally, found that being a woman, a minority, married, college-educated, employed, and having a higher income all decreased the odds of having sought treatment in the past year.¹²

Discussion

The articles reviewed here provide a mixed picture as to the influence of stigma on treatment decisions in those with a need for treatment for alcohol or drug use. Seventy percent of quantitative studies that provided frequency information for stigma as a treatment barrier reported low rates, with stigma

ranging between the most and 13th-most frequently cited barrier. All studies reporting high frequency for stigma were cross-sectional and thus incapable of prospective prediction of treatment utilization, whereas ten of the studies with low frequency were longitudinal in nature.

That said, frequency itself is not necessarily the variable of most interest. A barrier might occur only in a small number of people and yet be highly influential for those individuals. Only three studies in this review asked participants to rate the influence of stigma on their treatment-seeking decisions: in these, stigma ranged from the most influential to eighth-most influential barrier. The study where stigma was rated as most influential included only 39 alcohol users,⁴³ while the other two studies included 218⁴² and 346 individuals.⁷ With so few studies, such low sample sizes, and such mixed findings of influence strength, it is unwise to make strong claims about the ultimate influence of stigma on treatment decisions in the larger population of substance users.

Statistical prediction of treatment utilization also showed mixed results in the studies reviewed. Five studies found that stigma was a positive predictor or copredictor, three that it was negative predictor or copredictor, and three that it was not a predictor at all. Of the positive (co)predictor studies, two looked at stigma within a larger category of barriers,^{54,65} two probed the stigma of being a user (as opposed to the stigma of getting into treatment),^{63,64} and one looked at individuals who had experienced a significant health event related to their use.⁶⁰ It stands to reason that measuring stigma within a larger category loses some specificity in terms of the direct impact of stigma on treatment-seeking decisions. Additionally, probing stigma of use is quite different from probing the stigma of getting treatment. It is easy to understand why someone might feel pressure to get help if it were known they had a problem with drugs or alcohol, whereas due to secretive coping strategies, many users may actually be able to maintain a degree of privacy concerning their use that would be lost by seeking treatment. Therefore, this collection of studies does not provide strong evidence of a positive influence of stigma on treatment seeking.

In terms of negative (co)predictor studies, the first was cross-sectional data from a longitudinal study.¹⁵ Another article from the same longitudinal study, but using two waves of data, found that stigma was not a predictor of treatment use,¹³ calling into question the utility of cross-sectional data in assessing this relationship. The second negative study found stigma was influential only when present for two statuses (ie, user and HIV-positive),⁶¹ supporting the idea that confounded multiple stigmas may be highly influential, but not providing

good evidence of a singular effect of substance-related stigma. Finally, the third negative study was conducted in college students (as opposed to a sample of only those with substance-use disorders) and measured only “help-seeking interest”, not actual use of services,⁶² making this study a measure of theoretical attitudes, rather than actual behavior in a population in need of treatment. As such, these studies are not particularly convincing either.

Of the studies that found no relationship between treatment seeking and stigma, two were longitudinal^{13,59} and one was not.⁴² One of the longitudinal studies only looked at stigma as a predictor indirectly through its relationship to race,⁵⁹ and the cross-sectional study grouped stigma with all perceived barriers to treatment.⁴² The remaining longitudinal study¹³ is somewhat more convincing, in that it is a report from a nationwide study and contains two waves of data. On balance, however, this group of studies is no more convincing than those that found a relationship between stigma and treatment-seeking decisions.

On more steady ground is the finding that multiple stigmas together can have compounded influence on treatment-seeking decisions. Thirty studies (47%) found evidence of the increased influence of compounded stigmas or a relationship between stigmatized demographic variables (ie, being a woman or minority) and treatment-seeking decisions. However, recognition of this fact may have contributed to the development of more culturally appropriate treatment programs for people with these compounded stigmas,⁷⁹ and thus the gap for sex and racial groups to access care, while still present, may have narrowed in recent years.⁸⁰

The mixed results reported in this review are somewhat disheartening, given the number of studies included. However, as previously alluded to, one major factor in this problem is likely related to varying definitions and measurement of the constructs of interest. Stigma is a complex construct, and is thus difficult to define and measure. There are different sources of stigma, including social institutions, public opinion, and the self. Moreover, these sources are all interconnected. For example, self-stigma is thought to develop as external stigma internalized by the individual.⁸¹ It is also the case that stigma can range from extremely subtle perceptions, which themselves may arise from objectively observable external sources or from subjective inner perceptions, to blatant discrimination practices. In terms of drug and alcohol use, there are also different targets of the stigma: there is the stigma of being a user itself, there is the entirely separate stigma of being someone who needs help with their use, which is activated when one seeks treatment

services, and there is differentiated stigma, depending on the substance being used.⁸² Finally, there is also the problem of multiple compounded stigmas. Many people who fall into one stigmatized category (eg, drug user) also fall into other such categories (eg, incarcerated individual, bisexual, female). Locating the boundary between one stigma and the next is difficult, if not impossible, and thus their impact must often be assessed together, rather than individually.

Beyond simply defining stigma, researchers have measured it in a number of ways, making it somewhat difficult to pull all the literature together coherently. Some measured stigma within a larger category (eg, acceptability of treatment), some measured one type or the other (eg, social stigma vs self-stigma) alone, others measured components of stigma that they had defined in various ways (eg, perceived devaluation), and still others measured stigma-related concepts (eg, fear of what others think or embarrassment). This lack of standardization must be considered when attempting to determine why one study may find a relation between (whatever they are calling) stigma and treatment seeking, while another does not. A secondary consequence is that there are not a large number of studies with the same measure of stigma to aggregate in a meta-analysis, which would be the best way to determine the strength of the evidence for any effect.

In addition to the complexity in defining and measuring stigma, there is the complexity of human motivation to consider. In a number of studies, the most frequently cited reasons not to seek treatment were not being ready to stop using,^{10,12,52} not accepting that there was a problem with use,^{13,39,42,50,51} or other attitudes about treatment.^{8,11,14,44,45,47,48} Stages of readiness to change must be considered when looking at the impact of stigma,^{60,62,83} as it stands to reason that someone who does not recognize they have a problem with drug or alcohol use at all will not be particularly influenced by perceived stigma against substance-use treatment, as the idea of getting treatment does not enter their consciousness. In other words, if one wishes to measure the influence of stigma on treatment seeking, first one must know where the sample falls in terms of problem recognition. Indeed, modern substance-use-treatment approaches are centered on the stages-of-change model.

Another factor to consider is treatment history. Notley³³ suggests that studies in this area should consider those who have a previous treatment history separately from those who have not. Having been through the process before exposes one to actual experiences of various types of stigma, as opposed to the anticipation of stigma in those who have not yet sought any treatment. Indeed, veterans who had attended at least nine

mental health-treatment sessions had higher stigma scores than those who had not,⁸⁴ a finding that one might reasonably suspect would be relevant in the case of drug- and alcohol-use treatment. Therefore, stigma may have a different level of influence in each population. Relatedly, a common theme in a number of studies in this review was that the source of stigma matters. In particular, it seems that nonjudgmental acceptance from staff at health care and substance-treatment facilities might be instrumental in overcoming negative emotions, self-stigma, and perceived social stigma associated with treatment, whereas staff who propagate stigma in populations with drug- or alcohol-use problems discourage these individuals from seeking or remaining in treatment.

In summary, this review of the literature found that while stigma may be frequently cited as a barrier to treatment in some samples, it is unclear if it is a particularly influential one. Clearly in some cases it is highly influential, such as when multiple stigmas are compounded, or when the stigma is being experienced or anticipated from staff at rehabilitation facilities or programs. But there are also clearly times when stigma is not the main concern, most especially when the user does not recognize their use as problematic. In a similar vein, sometimes stigma is not perceived as such directly, but can be seen in indirect ways (eg, worried about what others will think, feelings of embarrassment). Without concentrated efforts to standardize the definition and measurement, the exact magnitude of the effect of stigma on treatment-seeking decisions, if any, will almost certainly remain unknown.

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