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# The Associations among Perceived Courtesy Stigma, Health and Social Behaviours in Family Members and Friends of People Who Use Substances: An Ecological Momentary Assessment Study

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## ABSTRACT

**Background:** The stigma and discrimination experienced by individuals with an alcohol/substance use disorder often extends to the family members and friends who provide care, which is known as courtesy stigma. This courtesy stigma can lead to isolation, poor mental health and might impact the quality-of-care these individuals provide. The aim of this study was to examine the frequency of experienced courtesy stigma/discrimination in individuals in a family support service for a loved one's substance use, and to examine any cross-sectional associations with changes in mood, health- and social-related outcomes. **Methods:** Thirty-six individuals (25 female) with a mean age of 51.91 years took part in an ecological momentary assessment study in which the experience of courtesy stigma/discrimination and measures of mood, health (e.g. alcohol use, nicotine use, healthy eating, sleep, physical activity) and social connections were taken 3 times per day for fourteen days. **Results:** Across 1029 completed assessments (compliance ~68%), there were 122 (~11%) reports of courtesy stigma/discrimination. The most common sources of stigma/discrimination were from family members (~43% of occurrences) and friends (~31% of occurrences). Experiencing this stigma/discrimination was associated with increases in alcohol and nicotine use, as well as reductions in healthy eating, physical activity, sleep, social connections, and mood. **Conclusions:** The experience of courtesy stigma/discrimination was common in a sample of individual's who support a loved one with alcohol or substance use disorder. These experiences are associated with changes in health and social behaviors and may lead to a poorer quality of care.

## KEYWORDS

Alcohol; discrimination; ecological momentary assessment; substance use; stigma



## Introduction


Alcohol and Substance Use Disorder (A/SUD) not only pose a significant burden to individuals but also contribute to broader societal challenges. A/SUD is a stigmatized condition (Kelly et al., 2021; Pennington et al., 2023), with estimates of the prevalence of stigma and discrimination for individuals with a diagnosis of A/SUD often greater than other issues such as mental health problems, as individuals are more likely to be blamed for their alcohol/substance use (Schomerus et al., 2011; Yang et al., 2017). For instance, in a sample of 197 individuals receiving treatment for substance use disorder, 60% reported being treated unfairly because of their substance use (Luoma et al., 2007). Furthermore, the experience of stigma and discrimination doesn't end after recovery. In a sample of over two-thousand individuals who no longer reported issues with alcohol or drug use (Vilsaint et al., 2020), approximately 22.9% reported at least one 'micro-discrimination' (i.e. a personal slight: 'being disrespected' or 'avoided'), as well as a variety of 'macro-discriminations' (i.e. violations of rights, such as denied

housing (9.4%) or receiving inadequate medical treatment (18.5%)), because of their alcohol or drug use history.

Stigma is a complex and multicomponent process, which includes self (internalization of stigmatizing views) and interpersonal stigma (the stigmatizing attitudes experienced from other), as well as structural stigma (Hatzenbuehler, 2016; Link & Phelan, 2001). Structural stigma is embedded in larger sociocultural contexts and can include institutional policies which limit or restrict opportunities (such as housing/treatment), as well as cultural norms which socially devalue individuals, or negative media portrayals of individuals with A/SUD (McNeil, 2021). Importantly, these processes are not mutually exclusive and can overlap and interact to contribute to the experience of stigma.

The impact of these different forms of stigma and discrimination on individuals with A/SUD is extensive. It can negatively impact both mental and physical health (Earnshaw et al., 2022; Lei et al., 2021), as well as exacerbating further substance use (Kulesza et al., 2014). It can reduce treatment seeking, lead to a poorer quality of care, or a refusal of treatment by health professionals (Ahern et al., 2007; Volkow,

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2020). This is despite efforts to reduce stigmatizing attitudes by framing A/SUD as a medical condition, rather than a moral failing (Heilig et al., 2021).

The experience of stigma and discrimination is not limited to the person with a A/SUD. Family members or friends who care for those with A/SUD also report experiencing stigma and discrimination, often referred to as 'secondary' or 'courtesy stigma'. Qualitative studies have suggested experiences of courtesy stigma are relatively common, come from multiple sources (O'Shay-Wallace, 2020), and can negatively impact mental health and social relationships through increased isolation and social rejection (Earnshaw et al., 2019; Liahaugen Flensburg et al., 2023). As with primary stigma, courtesy stigma is often worse for family/friends of individuals who have an A/SUD relative to other health conditions. In a hypothetical vignette study in the general public, Corrigan et al. (2006) demonstrated that stigma received by family members (e.g. being blamed for relapse) of those with substance use problems was greater than relatives of those with schizophrenia and emphysema.

Experiencing courtesy stigma may have a downstream effect on support of loved ones with A/SUD (Earnshaw, 2020). For instance, caregivers may distance themselves to manage feelings of stigma or shame (Luoma, 2011), which then impacts on, and reduces, the care they provide. This is a considerable issue, as caregivers are the often the primary source of emotional and instrumental support, and this support is predictive of positive outcomes during and following recovery (McGaffin et al., 2018). Despite this, very little research has focused on the lived experience of stigma and discrimination of family/friends who care for individuals with A/SUD, and the impacts this stigma may have on mood, health and social behaviors.

In this study, we used an ecological momentary assessment (EMA) design (Shiffman et al., 2008) to examine experiences of stigma and mood, health and social-related outcomes over time, in those with a caring role for someone with A/SUD. This allows us to overcome issues with long-term retrospective recall of experiences which can be forgotten or influenced by mood/context (Potter et al., 2021), but also examine *within* individual changes in mood, health and social behaviors as a result of experiencing courtesy stigma. We hypothesized that experiencing stigma would increase unhealthy behaviors (e.g. alcohol use, smoking, gambling) and reduce healthy behaviors (e.g. social connecting, physical activity, sleep) and momentary mood.

## Methods

### Participants

Thirty-six individuals (25 female) with a mean age of 51.91 years were recruited from a local family support service for individuals with A/SUD. The service supports family members and concerned others that have been impacted by a loved one's A/SUD. This is achieved through creating connections and providing information and education to help build resilience and wellbeing, *via* educational workshops and peer led support delivered in both 1:1 and group settings. In order to participate individuals had to be aged 18+

and support a family member or friend with alcohol or substance use disorder. Individuals who also self-reported a current or historic diagnosis of alcohol/substance use disorder or psychiatric disorder were excluded. As this was a pilot study, we aimed for at least 30 participants, based on Kreft et al.'s recommendations (1996), however we also conducted a multilevel power analysis using the 'mixedpower' package in R. We estimated a beta value for the effects of stigma on our outcomes of  $\sim B=0.15$  (smaller than estimates of primary stigma on depression/sleep reported elsewhere (Birtel et al., 2017)) assuming a linear trend; an Intraclass Correlation Coefficient of  $\sim 0.35$ ; and intercept of 3.00. Thirty participants would give 97% power with full compliance and 79% power with 50% compliance.

## Materials

### Baseline questionnaire

Participants completed a baseline questionnaire, in which they provided their age (years) and gender (male/female/non-binary/other). They were also asked about their connection to the person with the substance use disorder, including their relationship (spouse/parental/other); primary substance (alcohol/opiates/other), living situation (same household/different household/other), and diagnosis (current/historic), and how long (months) they had been in treatment.

### Ecological momentary assessment questions

**Stigma.** The repeated daily survey asked about stigma ('Have you experienced any stigma or discrimination due to your family member/loved-one's addiction, since the last prompt' [YES/NO]). If they answered yes, a follow up question asked about the source of the stigma ('If you experienced stigma/discrimination. Was your experience from a...' [Family Member, Friend, Member of the Public, Healthcare professional, Other]).

**Mood.** Participants were asked to rate their current mood using a 7-point Likert scale from -3 (Extremely low mood) to +3 (Extremely good mood) with 0 (neutral) mood.

### Health-related behaviors

Participants were asked about the frequency of 7 health-behaviors since the last prompt, including; smoked nicotine/consumed alcohol/gambled/connected with others (social connections)/eaten healthily/physical activity/slept) on a 5-point Likert scale (1=less than usual to 5=more than usual). If the behavior was not applicable to the participant (e.g. they were a non-smoker) they stated this. Behaviors of interest were chosen in discussion with staff members and individuals at the service.

## Procedure

Participants were recruited through referrals from a family support service for family members/friends who were impacted by a loved one's substance use disorder, in the

northwest of England, UK. Referrals into the service primarily come from the local drug and alcohol treatment provider, as well as self-referrals directly to the service. Those who wished to participate in the study had a familiarization session with a researcher (DS) and had the study procedure and questionnaires explained, before providing consent.

Participants either completed the baseline information *via* the web or at the family support service with the researcher. They also provided contact details (email or telephone) to receive scheduled reminders at three times per day (8 am/2 pm/8 pm) for fourteen days to complete measures of stigma, mood and health-related behaviors. To increase accessibility and data yield, any individuals who wanted to participate but didn't have confidence with the EMA procedure/technology, completed a daily paper and pencil version which was uploaded directly by the researcher on Mondays/Wednesdays/Fridays (3 participants: removal of these participants did not significantly alter the findings, shown below). Each EMA assessment took approximately one minute to ensure limited participant burden. Data was collected using Inquisit Web (Millisecond Software). We were unable to offer any reimbursement for participants taking part in this study. The study was approved by the local research ethics committee at Liverpool John Moores University.

### Data reduction and analyses

To examine compliance, we conducted a multilevel binomial logistic regression on assessment compliance (1=complied, 0=missing). We included age and gender as predictors, in line with previous research suggesting demographic characteristics are associated with compliance (Martinez et al., 2021; Sokolovsky et al., 2014). Similarly, we included assessment number (1–42) to examine any reductions in compliance over time, as reported elsewhere (Jones et al., 2020; Tonkin et al., 2023).

To examine associations between reported stigma/discrimination, mood and health and social related behaviours we conducted multilevel ordinal regression models using the 'brms' package in R, and obtained frequentist pvalues using the 'ordinal' package. We used multilevel models as intensive longitudinal data has a hierarchical structure of assessments nested with individuals (Brown, 2021), and included a random intercept for participant. In several simple models we examined the predictor of stigma/discrimination experience (1 = yes / 0 = no) on mood, health and social behaviour change reporting. We also adjusted models for age and gender. We did not report linear models given criticisms by Jamieson (Jamieson, 2004) of using Likert style data in these models, however we note that treating the data as linear did not significantly alter findings. Data and analysis scripts are available here: <https://osf.io/rgqx3/>

## Results

### Participant demographics

Participant demographics are shown in Table 1.

### Compliance

Overall, 68% (1029 of a possible 1512) of assessments were completed. Participant level compliance ranged from 12% (5/42) to 100%. Participant age was a negative predictor of compliance (OR = 0.97 95% CI: 0.94 to 1.00],  $p=0.046$ ), as was assessment number (OR = 0.98 [95% CI: 0.97 to 0.99],  $p=0.001$ ). However, gender was not (OR = 1.91 [95% CI: 0.79 to 4.62],  $p=0.152$ ).

### Prevalence and sources of stigma and discrimination

Overall, there were 122 (11% of assessments) instances in which stigma and discrimination reported, with 10 individuals not reporting any incidences of stigma. Of those that did report stigma the average number of reports was 4.69 (SD = 2.65, Min = 1, Max = 9). Descriptively, males (Mean = 4.67, SD = 3.20) and females had similar frequency of reports (Mean = 4.53, SD = 2.51). Similarly, frequency of reports were similar if family member or friend was receiving treatment for Alcohol (Mean = 4.82, SD = 2.81) or Opiates (Mean = 4.38, SD = 2.33). Reporting was somewhat greater if a family member or friend had a current addiction (Mean = 4.79, SD = 2.55), compared with historic diagnosis (Mean = 3.83, SD = 2.93). Finally, reporting was higher if it was a spouse (Mean = 5.33, SD = 2.50) or parent (Mean = 4.67, SD = 2.81) compared to 'other' (Mean = 2.50, SD = 1.29).<sup>1</sup>

Of the 122 occasions, 52 (42.6%) reported stigma/discrimination from a family member; 38 (31.1%) reported stigma and discrimination from a friend; 13 (10.7%) from a healthcare professional; 8 (6.6%) from a member of the public, and 6 (4.9%) from other sources.

### Is stigma and discrimination associated with changes to mood, health and social behaviors?

Cross sectional associations suggested the experience of stigma decreased self-reported mood, sleep, healthy eating, physical activity, and social connections, as well as increased

**Table 1.** Participant demographics and information on loved one's circumstances.

	Mean (SD)	Range
Age	51.91 (12.56)	30–75
Time in treatment (months)	4.5 (5.30)	0–12+
	N	(%)
Gender: Male	10	28.5%
Gender: Female	25	71.5%
Status: Current	27	77.1%
Status: Historic	8	22.9%
Substance: Alcohol	22	62.6%
Substance: Opiates	10	28.6%
Substance: Other	3	8.8%
Family: Spouse	12	34.3%
Family: Parent	15	42.9%
Family: Other	8	22.8%
Living: Same household	13	37.1%
Living: Different household	21	60.0%
Living: Other	1	2.9%

Note: Demographic data from one participant was lost due to technical issues, therefore  $N=35$  in Table 1.



**Table 2.** Cross sectional associations between stigma experience and changes in mood, health and social-related behaviors.

	OR	95% CI	p	N
Mood	0.24	0.19 to 0.30	<.001	1028
Alcohol use	2.28	1.67 to 3.14	<.001	454
Nicotine	6.45	4.22 to 9.96	<.001	363
Gambling	1.02	0.66 to 1.58	.780	192
Sleep	0.39	0.28 to 0.54	<.001	520
Health eating	0.48	0.38 to 0.60	<.001	1011
Activity	0.41	0.33 to 0.51	<.001	983
Connected	0.48	0.38 to 0.59	<.001	962

CI=credible intervals; OR=odds ratio; N=number of data points analyzed; pvalue for frequentist model.

alcohol and nicotine use (see Table 2; Supplementary Figures 1–8). There was no effect on gambling. These associations remained significant when adjusting models for age and gender.

## Discussion

The aim of this EMA study was to examine the associations between perceived stigma and discrimination experienced by family members or friends of someone with A/SUD, and their health-related behaviors. The findings suggest that experiencing courtesy stigma/discrimination is a relatively common occurrence, and has a broad negative impact on individuals' mood, as well as health-related behaviors.

To our knowledge, this is the first study quantitatively examining the lived experience of interpersonal stigma and discrimination of individuals who care for somebody with A/SUD. Our findings support qualitative research and hypothetical studies which suggest the pervasive nature of courtesy stigma (Earnshaw et al., 2019; Liahaugen Flensburg et al., 2023). Participants reported various sources of courtesy stigma/discrimination with the most common being family and friends (similar to other types of stigma, such as weight-related (Himmelstein & Puhl, 2019)).

Participants also reported stigma and discrimination from healthcare professionals (Houghton & Taylor, 2021; van Boekel et al., 2013). This may lead to avoidance of interactions with healthcare workers, which could also be disastrous if potential overdose or harm has occurred to the individual with the A/SUD and healthcare is required (Aronowitz & Meisel, 2022), but may also lead to the avoidance of their own health needs.

Experience of courtesy stigma was associated with cross-sectional reductions in positive mood, as well as negatively affecting health and social behaviors. Specifically, experiencing stigma reduced sleep, healthy eating, physical activity, and social connection while increasing alcohol and nicotine use. These effects could impact the individual's health and wellbeing, but also the quality of care they provide. Given these observations, it is important to develop interventions which might include friends/family, but also educate the general public, and mental health professionals to stigma/discrimination (Aronowitz & Meisel, 2022; Zwick et al., 2020) in order to reduce these direct and indirect impacts.

We provided some estimates of the prevalence of experiencing courtesy stigma in individuals. However, it is possible that these are underestimates. Whilst EMA designs have considerable benefits in measuring 'in the moment' occurrences, it is possible that individuals do not *immediately* recognize experiencing stigma or discrimination and only realize some time later. In support of this, there are reported links between ruminating and stigma in EMA designs (Hatzenbuehler et al., 2009). Similarly, individuals may choose to conceal a potentially stigmatizing identity from others to reduce the possibility of interpersonal stigma (Camacho et al., 2020). This can be particularly damaging as exposing a stigmatizing identity to friends and family has been associated with greater social support.

Whilst this study was a pilot design, there are a number of limitations which should be addressed. First, we did not use validated tools to assess health-related behaviors or stigma (D'Aniello et al., 2022; Sobell et al., 1996), as our aim was to use relatively simple and easy to complete questions to reduce participant burden (Smyth et al., 2021). Future research should consider including validated questionnaires, but also to examine other behaviors which might be influenced by stigma and discrimination (e.g. mental health, drug use), but also how the response to discrimination might impact these outcomes (Ahern et al., 2007). Second, our compliance rates were lower than typically reported for some EMA designs (Jones et al., 2019), which could be explained by a lack of reimbursement offered to our participants (Wrzus & Neubauer, 2022). Third, our focus was on interpersonal stigma, and there was no focus on stigma at structural levels. Finally, we did not ask participants about specific forms of stigma (e.g. denial of care, judgemental attitudes) and future research should examine the prevalence of specific forms and their associations with health and social outcomes.

In conclusion, family members and friends of individuals with A/SUD can experience courtesy stigma, which may impact their mood and health-related behaviors. This could result in a number of costly issues *via* harm to their own physical and mental health and impairment of informal care roles.

## Note

1. Estimates reported only descriptively due to small sample size.

## Disclosure statement

The authors declare that no grants were involved in supporting this work.

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## Data availability statement

Data and analysis scripts are available for this project at OSF link <https://osf.io/rgqx3/>.

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