
Help-seeking behaviour among illegal substance users

ORIGINAL ARTICLE

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BACKGROUND

The purpose of the study was to investigate health-related help-seeking behaviour among illegal substance users.

MATERIAL AND METHOD

Data were collected on the website Rusopplysningen.no. Questions were asked about use of illegal substances and openness with healthcare personnel regarding this use. Only respondents who reported having used illegal substances were included, and missing responses to particular questions were excluded from the percentage calculations.

RESULTS

Altogether 2 485 respondents had used illegal substances. A total of 880 (39 %) had told healthcare/social care personnel about their substance use, of which 506 (68 %) reported that they had no need of help. Altogether 802 (36 %) had avoided telling healthcare/social care personnel about their use of illegal substances in relevant situations, while 309 (14 %) believed that they needed treatment for substance use, and 202 of these (65 %) had avoided or postponed seeking such treatment. Among the 815 who had been in an acute medical situation related to substance use, 82 (10 %) had delayed calling an ambulance, and 330 (41 %) had avoided calling an ambulance altogether. Among these, fear of being reported to the police was the most frequently reported reason (n = 280, 71 %), while 216 (55 %) reported that they had not considered an ambulance to be necessary.

INTERPRETATION

Many users of illegal substances do not reveal this to healthcare personnel. Some also avoid calling an ambulance in acute substance-related situations. Fear of police sanctions appears to be a plausible contributory factor.

Main findings

Many users of illegal substances had not told healthcare/social care personnel about their substance use. The majority of those who believed that they needed treatment for substance use had avoided or postponed seeking such treatment.

Among those who had disclosed their use of illegal substances to healthcare/social care personnel, some believed that it had had negative consequences for them.

Some avoided or postponed calling an ambulance in acute substance-related situations.

During the course of their life, many people will satisfy the criteria for a substance-related diagnosis, but few generally seek help, particularly young people [\(1\)](#). Shame and concern about being socially stigmatised seem to be common factors in this [\(2\)](#). There is a commonly held view that the criminalisation of drugs plays a role here for users of illegal substances [\(3, 4\)](#). Nevertheless, it has been documented that the most active users in Norway, more specifically those who have died of a substance-related overdose, have

often had contact with the support services (5). We have limited knowledge of help-seeking behaviour among the much larger group of low-frequency users and those with a more controlled use of illegal substances.

Using illegal substances is a criminal offence, which can lead to methodology problems, underreporting and participant withdrawal from surveys and follow-up studies (6, 7). The response rate has been declining in such studies (8, 9). The population is also hidden, as illegal use typically takes place in the private domain. Much of the knowledge therefore relates to selected subgroups (10). We know a lot about users who are included in registers due to criminal activity or treatment for substance use (11), as well as users who frequent nightclubs etc. where illegal substances are typically found (12). We also have data on users who are included in school surveys (13). However, help-seeking behaviour is seldom the focus, particularly in relation to the last two groups of studies.

In order to investigate health-related help-seeking behaviour in connection with the use of illegal substances, we analysed data from a survey on the website Rusopplysningen.no. We recorded whether the respondents were open about their own drug use in their contact with healthcare/social care personnel and how they behave in acute substance-related situations.

Material and method

The data material was collected via Rusopplysningen.no, an online project run by the Association for Safer Drug Policies, which is working 'to replace punishment and alienation with education, human rights, harm reduction and compassion' (14). The project is funded by the Norwegian Directorate of Health and is a collaboration with HivNorway and Gay and Lesbian Health Norway. The website provides information about the effects and risks of using alcohol and illegal substances and the 'precautions' that should be taken. Participants were also recruited to the survey from drug policy organisations and websites that discuss substance use (ChemFriendly, EmmaSofia, Normal Norway, the Association for Humane Drug Policy in Norway, Freakforum and Reddit). These responses were omitted from our analysis. Our data were collected between 5 September 2020 and 1 January 2021.

The authors were not involved in devising or conducting the survey; this was done by the Association for Safer Drug Policies, which made the material available to the authors without setting conditions or requesting compensation.

All visitors to Rusopplysningen.no were invited to participate in an anonymous survey. Questions were asked relating to age, gender, employment status, use of illegal substances and various topics concerning openness about use with family, friends, the health service and whether and how illegal substance use was something that was discussed during any contact with the health service. The questions were not validated or based on earlier research. Participants were mainly asked to select a response from the given alternatives. A complete overview of questions and response categories in the survey is given in the appendix.

Here we analyse questions concerning the use of health services (Table 1). Only those who were recruited via Rusopplysningen.no and who indicated that they had used illegal substances are included in the dataset. Non-responses are not included in the percentage calculations.

Table 1

Health-related questions in the survey on the Rusopplysningen.no website in the period 5 September 2020–1 January 2021 that are used in this study.

Text used in tables	Full text used in the survey	Response alternatives
Told healthcare/social care personnel about use	Have you ever told a doctor, psychologist or other healthcare/social care professional that you have used illegal substances?	'Yes' 'No'
Received help after disclosing use	Did you get the help you needed after you disclosed your use of illegal substances?	'No' 'Yes' 'Did not need help'
Negative consequences of openness about substance use with healthcare/social work personnel	Did you experience any negative consequences after disclosing your substance use?	'No' 'Yes (specify)'
Did not give healthcare/social care personnel information about illegal substance use when relevant	Have you ever avoided telling a doctor, psychologist or other healthcare/social care professional that you have used an illegal substance when it would have been relevant to do so?	'Yes' 'No'
Avoided or postponed seeking treatment for substance use	Have you ever <i>avoided</i> or <i>postponed</i> seeking treatment for illegal substance use, even though you thought you needed treatment?	'Yes' 'No, I have sought treatment when I thought I needed it' 'No, I have never thought that I have needed treatment'
Experienced substance-related acute medical situation	How many times have you been in a situation where someone overdosed, became psychotic, had another serious, worrying reaction or was seriously injured after taking an illegal substance?	'Never' 'Once' '2-5 times' '5-10 times' 'More than 10 times'
Postponed or avoided calling an ambulance in an acute substance-related situation	Have you ever in such an event experienced that an ambulance was <i>not</i> called, or that you <i>waited</i> to call an ambulance, even though you thought that the person needed immediate help?	'No, an ambulance has <i>always</i> been called immediately' 'Yes, I have experienced that an ambulance has not been called' 'An ambulance has always been called, but I have experienced this being postponed' 'Don't know/not sure'

Text used in tables	Full text used in the survey	Response alternatives
Reasons for not calling an ambulance	What reasons, if any, were given for not calling an ambulance?	(<i>Select all answers that apply.</i>) 'Ambulance was not considered necessary' 'Fear that the police would be notified' 'Fear that other government agencies would be notified' 'Fear that parents/guardians would be notified' 'Other reasons (specify)'

The participants gave their consent to the results being used in research. The data material is anonymous, and the implications for privacy were assessed by the data protection officer at the Frisch Centre (DPIA, archive reference 4901).

Results

The starting point was 3 046 responses from visitors to Rusopplysningen.no. Of these, 2 485 indicated that they had used illegal substances, and these were included in the material.

Table 2 gives an overview of the sample. The majority were men ($n = 1\,724$, 70 %) aged 18–34 years ($n = 1\,723$, 69 %), who were either students ($n = 961$, 39 %) or in full-time employment ($n = 855$, 34 %). A total of 1 343 (54 %) had used an illegal substance in the preceding week, and 488 (20 %) had had contact with the police or judicial system due to such use.

Table 2

Characteristics of persons who responded to the survey on the Rusopplysningen.no website in the period 5 September 2020–1 January 2021, and who indicated that they had used illegal substances ($N = 2\,485$). See the appendix for questions and response alternatives.

Variables	Number (%)
Gender	
Female	712 (29)
Male	1 724 (70)
Non-binary	31 (1)
Other	9 (0)
No response given	9
Age	
Under 18	296 (12)

Variables	Number (%)
18–24	1 017 (41)
25–34	706 (28)
35–44	286 (12)
45+	175 (7)
No response given	5
Employment status	
Student	961 (39)
Full-time employment	855 (34)
Part-time employment	161 (6)
Self-employed/freelance	106 (4)
Job seeker	102 (4)
On sick leave, receiving disability benefit, retired, other	298 (12)
No response given	2
Most recent use of an illegal substance	
Less than one week ago	1 343 (54)
Between one week and one month ago	408 (16)
Between one and three months ago	277 (11)
More than three months ago	457 (18)
Arrested by the police, convicted for use of illegal substance	
No	1 959 (80)
Yes, arrested but not convicted	168 (7)
Yes, both	320 (13)
No response given	38

A total of 880 (39 %) participants reported that they had told healthcare/social care personnel about their substance use (Table 3). Of these, 210 (24 %) believed that this had led to negative consequences. Of the 880 (68 %) who had disclosed their substance use, 506 said that they had not needed help, while 176 (20 %) indicated that they had received such help, and 191 (22 %) responded that they had *not* received such help after informing healthcare/social care personnel about their substance use.

in the period 5 September 2020–1 January 2021 and who stated that they had used illegal substances (N = 2 485). See

Table 3

Answers to health-related questions in the survey on the Rusopplysningen.no website
Table 1 for the full text of the question and response alternatives.

Question and response alternatives	Number (%)
Told healthcare/social care personnel about use	
Yes	880 (39)
No	1 397 (61)
No response given	208
(Of those who told:) Received help after disclosing use?	
No	191 (22)
Yes	176 (20)
Did not need help	506 (58)
No response given	7
(Of those who told:) Negative consequences of openness about substance use with healthcare/social work personnel	
No	660 (76)
Yes	210 (24)
No response given	10
Did not give healthcare/social care personnel information about illegal substance use when relevant	
No	1 426 (64)
Yes	802 (36)
No response given	257
Avoided or postponed seeking treatment for substance use	
No, I have never thought that I have needed treatment	1 871 (86)
No, I have sought treatment when I thought I needed it	107 (5)
Yes	202 (9)
No response given	305
Experienced substance-related acute medical situation	
Never	1 315 (62)
Once	379 (18)
2-5 times	288 (14)
6 or more times	148 (7)
No response given	355
Of those who had experienced this at least once: Postponed or avoided calling an ambulance in an acute substance-related situation	
No, an ambulance has always been called immediately	186 (23)

Question and response alternatives	Number (%)
An ambulance has always been called, but I have experienced this being postponed	82 (10)
Yes, I have experienced that an ambulance has not been called	330 (41)
Don't know, not sure	210 (26)
No response given	7

A total of 802 people (36 %) stated that they had not told healthcare/social care personnel about their illegal substance use in situations where this would have been relevant information (Table 2).

Of the total sample, 309 respondents (14 %) thought they had needed treatment, and 202 of these (65 %) had avoided or postponed seeking such treatment in the health service. A total of 815 (38 %) stated that they had experienced at least one substance-related acute medical situation (Table 3). Half of these had experienced that those present either postponed (n = 82, 10 %) or avoided (n = 330, 41 %) calling an ambulance. The most frequently cited reason (sum of 'Fairly relevant' and 'Very relevant') among these 412 was fear that the police (n = 280, 71 %) or other public agencies (n = 235, 60 %) would be notified (Table 4), while 216 (55 %) indicated that an ambulance was not considered to be necessary.

Table 4

Stated reasons for not calling an ambulance in an acute substance-related situation. Survey on the Rusopplysningen.no website in the period 5 September 2020–1 January 2021, the sub-sample that stated they had used illegal substances and had been in at least one such emergency situation (N = 412). Forty-eight (12 %) cited 'Other reasons'. See Table 1 for the full text of questions.

Response alternative	Ambulance was not considered necessary, n (%)	Fear that the police would be notified, n (%)	Fear that other public agencies would be notified, n (%)	Fear that parents/guardians would be notified, n (%)
Not relevant	54 (14)	58 (15)	77 (20)	128 (32)
Not very relevant	28 (7)	16 (4)	20 (5)	33 (8)
Slightly relevant	64 (16)	30 (8)	45 (11)	44 (11)
Fairly relevant	113 (29)	69 (17)	77 (20)	56 (14)
Very relevant	103 (26)	211 (53)	158 (40)	117 (30)
Don't know if relevant	28 (7)	13 (3)	17 (4)	16 (4)
No response given	22	15	18	18

Discussion

The study sheds light on young adults with experience in the use of illegal substances who had actively sought out a website that provided information about possible health risks and precautions related to substance use. The majority were students or in employment. Only 14 % stated that they needed treatment for substance use, and a minority had experienced being arrested by the police for illegal substance use (20 %).

Just over a third of this sample had refrained from telling healthcare personnel about their substance use in situations where it would have been relevant to do so. Many had experienced that an ambulance was not called in acute substance-related situations. Among those who had told healthcare personnel about substance use problems, one in four thought it had had negative consequences for them. However, there were also a good number who had disclosed their use of illegal substances but who did not believe that they needed medical assistance. The picture is thus somewhat mixed.

In relation to alcohol, the so-called prevention paradox means that the predominance of injuries is found in moderate users, who, despite the lower risk of injury, constitute a much larger group than extremely heavy users (15). A different picture emerges when considering illegal substances as a whole: the Norwegian Institute of Public Health's latest figures estimate that only around 9 000 people are involved in high-risk use of opioids in Norway (16). The concentrated health burden in this group is estimated at 300 disability-adjusted life years (DALY) per 100 000 inhabitants, while the corresponding health burden in the much larger group of cannabis users is estimated to be 8 DALY (17). The most serious substance use disorders involve ill health and considerable suffering. They are also difficult to treat and often only appear following many years of substance use. Breaking down barriers to seeking help among relatively new users can therefore be an important preventive measure. In addition, there is probably a generally unmet need for medical assistance related to illegal substance use among the many who never become heavy users.

In our study, there appear to be several reasons for postponing or avoiding calling an ambulance in acute substance-related situations. The majority stated that they had feared that the police and/or other public agencies would be notified. However, it should be noted that more than half thought that calling an ambulance had not been considered necessary. This may seem contradictory, and we discuss this matter below. We also want to emphasise that the data do not make it possible to ascertain whether the situations in question actually involved potentially life-threatening events.

A Swedish study found similar scepticism to calling for help in acute medical situations in a sample of mainly moderate users of illegal substances. Here, 32 % stated that they would hesitate, while 8 % were adamant they would not seek help in a situation where substance use constituted an acute threat to

health or the risk of overdose (18). The main reasons cited were fear of the police, of being socially stigmatised, of having their home searched and of getting into trouble with the child welfare service.

Fewer people with mental illnesses seek medical assistance than those with somatic diseases (19), and those with substance use disorders are the least likely to seek help (1). There can be several reasons for this. Some people may find that the benefits of using substances and the enjoyment it gives them outweigh the potential harm it may cause, and therefore do not want to tell healthcare personnel about their substance use, or they may underestimate the actual risk (20). However, shame and concern about being socially stigmatised are also likely to be factors, especially in the case of illegal substance use (2). There is also a commonly held view that the criminalisation of the use of illegal substances plays a role (3, 4). Our findings may indicate that fear of notifying the police comes into play in acute situations, but we do not know whether the fear concerns the involvement of the police themselves or the possibility of being convicted.

Healthcare personnel may also be unsure of what treatment they should offer patients with defined substance use disorders (21). A literature review showed that they can also perceive the patient group as manipulative and not motivated to get help. This may be partly due to a lack of professional training to deal with this patient group and the absence of good support in the working environment (22). It is therefore not surprising that many with diagnosed substance use disorders believe that the help they received was inadequate (23). One possible consequence is that both the group with diagnosed substance use disorders and other users of illegal substances instead seek help in their personal networks of other users or in online forums, where there may be scepticism both to established forms of treatment and to the healthcare professions (24).

One limitation of the study is that we do not use standardised or validated instruments. Additionally, some of the questions can be perceived as leading and some had a relatively high proportion of 'No' responses. The sample is also self-selected and cannot be considered representative of a clearly defined population of 'experimental users'. The high number who did not consider it necessary to call an ambulance but believed that immediate help was needed may have several explanations. It may be due to ambiguities in questions and response alternatives, or to respondents being confused about or not recognising the seriousness of acute situations triggered by substance use. Some of those who reported this may have been under the influence of drugs themselves, in which case it is conceivable that they viewed the situation differently to others present.

Another limitation is that users who have experienced acute situations triggered by substance use or are sceptical to disclosing their own problems to a doctor or other healthcare professional may be more likely to seek out a source of information such as Rusopplysningen.no, and heavy users are probably underrepresented. Neither names nor IP addresses were logged, and the possibility of some people participating more than once cannot therefore be ruled out. It is also conceivable that the website is associated with some of the organisations that have developed the support services. This particularly

applies to the Association for Safer Drug Policies, which operates the site and has another more drug policy-oriented website with a related visual design. We do not have the opportunity to shed light on such selection factors in our data.

The study also lacks a comparison group. We know that few people with alcohol problems seek help (25). Future studies should therefore include different groups of alcohol users, including those who share background characteristics with our sample. This will enable researchers to identify whether the mechanisms we allude to here are also to be found in relation to legal consumption.

We found that a significant proportion of the participants who self-reported the use of illegal substances did not disclose this to healthcare/social care personnel. As indicated by the majority of the sample, they probably have a limited need for treatment. Nevertheless, it is unfortunate that so many do not disclose their illegal substance use when it is relevant to do so, and that some have experienced an ambulance not being called in acute substance-related situations. The study also illustrates how websites visited by people who use illegal substances were a useful gateway to accessing the group we wanted to study: users of illegal substances who have typically not told healthcare personnel about their substance use and who have typically not been revealed to be users by police and the judicial system. It is thus not easy to identify this group in datasets extracted from public registers.

Since the authors started working with the data material, the Association for Safer Drug Policies has published its own review of the findings (<https://www.rusreform.no/underskelse-om-hjelpeskende-atferd>). The article has been peer-reviewed.

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