

The use of illicit drugs as self-medication in the treatment of cluster headache: Results from an Italian online survey

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Abstract

Background: Cluster headache (CH) patients often receive unsatisfactory treatment and may explore illicit substances as alternatives. We aimed to explore this use of illicit drugs for CH treatment.

Methods: We invited CH patients from an Internet-based self-help group to complete a questionnaire regarding their therapeutic use of illicit substances.

Results: Of the 54 respondents, 29 were classified as chronic and 39 were drug-resistant cases. Fifty patients had previously tried subcutaneous sumatriptan, 40 had tried O₂, and 48 had tried at least one prophylactic treatment. All 54 patients specified that they were dissatisfied with conventional treatments. Thirty-four patients had used cannabinoids, 13 cocaine, 8 heroin, 18 psilocybin, 12 lysergic acid amide (LSA), and 4 lysergic acid diethylamide (LSD).

Discussion: Some patients with intractable CH decided to try illicit drugs concomitantly with cessation of medical care. Most of these patients found suggestions for illicit drug use on the Internet. Many patients seemed to underestimate the judicial consequences of, and had an overestimated confidence in the safety of, such illicit treatments. Physicians are often not informed by patients of their choice to use illicit drugs. This leads to questions regarding the true nature of the physician-patient relationship among dissatisfied CH patients.

Keywords

Cluster headache, illicit drugs, psilocybin, LSA, LSD

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Introduction

Cluster headache (CH) patients explore both conventional and unconventional treatments (1) and are more prone to using illicit drugs (2). We recently received the unexpected request for a prescription for an illicit hallucinogen by a patient with CH to treat his headache (3). The effectiveness of hallucinogenic compounds has been supported by anecdotal scientific literature (4); however, controlled trials are still pending.

To deepen our knowledge about patients' recourse to illicit substances for CH treatment, we conducted a survey, carrying out direct interviews with CH patients. However, of the 110 patients with CH present in our database, only six had used illicit drugs (cannabinoids) exclusively for therapeutic purposes. The limited number of patients with illicit drug use induced us to extend the study to reach a wider patient base. We therefore used an Internet-based community, according

to previously published surveys on CH that used online questionnaires (5–7).

Thus, we posted an alert on the “time line” of a self-help group of Italian patients with CH (with more than 800 members) who were active on Facebook (<https://>

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www.facebook.com/groups/85237680625/), inviting patients to tell us about their experience of using illicit drugs for CH treatment. The aim of our study was to explore the use of illicit drugs for CH treatment among patients who were not using these substances for recreational purposes. In particular, we were interested in identifying which substances were used and what induced patients to try this alternative treatment option.

Methods

We developed a questionnaire to elicit socio-demographic data, previous experience with conventional CH therapies, the recreational use of illicit substances, and the lifetime use of these illicit substances to treat CH. This study was approved by our local ethics committee. Patients were asked to respond to an online interview, or to complete the questionnaire that was posted online during the months of May and June 2014. Patients who were diagnosed with CH by a neurologist (the diagnosis was not validated by the authors) and had not used illicit drugs recreationally during the previous year (self-reported) were considered eligible for the study. After completion of the questionnaires, data were anonymously entered into our database. All questionnaires and emails were then deleted from the computers and servers to maintain the confidentiality of the participants.

Results

Fifty-four patients (6.75% of the Facebook group members) confirmed using within their lifetime at least one illicit drug to treat CH. The participants stated that they had not used these drugs for recreational purposes, nor did they consume any illicit drugs for recreational use within the previous year. Of the 54 participants (35 men/19 women), 23 (42.6%) were married, 8 (14.8%) had a university bachelor's or post-graduate degree, 46 (85.2%) were employed, and 43 (79.6%) had a low household annual income (<36,000 €).

From a clinical point of view, when the participants first used illicit drugs, 29 (53.7%) cases were classified as chronic, 39 (72.2%) were drug resistant (refractory to all tried preventive pharmacotherapies), 41 (75.9%) patients had consulted at least three different headache specialists, and 40 (74.1%) had a consultation rate (number of headache-related visits during their lifetime) of >10. Fifty (92.6%) of the participants had tried subcutaneous sumatriptan, 40 (74.1%) had tried O₂ therapy (dose and delivery method unknown), and 48 (85.7%) had tried at least one prophylactic treatment (dosage unknown; 25 (46.3%) had tried at least three

different prophylactic treatments). All the participants reported that they were dissatisfied with conventional treatments in terms of their efficacy and/or tolerability.

Regarding the use of illicit drugs, only three (5.6%) of the participants received suggestions from their physician on using these substances. The rest of the participants (94.4%) received suggestions from other patients or found recommendations on the Internet. Prior to their first consumption of the illicit drug, 24 (44.4%, 15 men) patients had previously used an illicit substance for recreational purposes at least once, 22 (40.7%) had told their physician about their decision to use illicit drugs, choosing to do so despite dissuasion from their physician, and 18 (33.3%) did not undergo a medical consultation before the use of illicit drugs. After commencing illicit drug use for CH treatment, 30 (55.6%) decided not to undergo further medical consultations; 19 (35.2%) told their physician about their illicit drug usage, after which their physicians declared that they were unable to provide continuing care. The denial of further treatment by the physician did not induce patients to stop the illicit drug treatments.

Of the 54 participants, 34 used cannabinoids, 13 cocaine, and 8 intravenous heroin as abortive agents; 18 used psilocybin (PSI), 12 lysergic acid amide (LSA), and 4 lysergic acid diethylamide (LSD) as prophylactic agents. In 2 of the cases, PSI, LSA, and LSD were used at a sub-hallucinogenic dose. Patients' self-reports on the effectiveness of each substance are presented in Table 1.

Following the use of illicit drugs for CH treatment, 48 patients (85.7%) declared that they did not perceive these agents as less safe than conventional medical treatments; 30 patients (55.6%) even considered their use of illicit drugs safer than conventional medical treatments. If required, these patients stated that they would recommend such illicit drug treatment to other patients. Only 4 patients (7.4%) reported that the illicit nature of their treatment generated some concerns regarding potential legal consequences.

Discussion

This study is the first survey examining the consumption of illicit drugs by patients to treat CH. We identified the reasons that induced patients to resort to the use of illicit drugs, as well as the substances consumed. The responses of our sample are not representative of the whole CH patient population. Therefore, we need to interpret our results with caution. In fact, a selection bias could affect our observations due to the nature of the sample: Members of a self-help group are more likely to be patients with severe CH who are looking for alternative solutions to traditional treatment. Therefore, we did not include an estimation of the

Table 1. Effectiveness of each substance (patients' self-report).

Substance	Purpose	n (%)	Perceived efficacy	n (%)
Cannabinoids	Abortive	34 (63%)	Effective (fully or in part)	10 ^a (29.4%)
			Ineffective	19 (55.9%)
			Worsening	5 (14.7%)
Cocaine	Abortive	13 (24.1%)	Effective (fully or in part)	4 (30.8%)
			Ineffective	8 (61.5%)
			Worsening	1 (7.7%)
Heroin	Abortive	8 (14.8)	Effective (fully or in part)	7 ^b (87.5%)
			Ineffective	1 (12.5%)
			Worsening	0
LSD	Prophylactic	4 (7.4%)	Effective (fully or in part)	3 (75%)
			Ineffective	1 (25%)
			Worsening	0
LSA	Prophylactic	12 (22.22%)	Effective (fully or in part)	9 (75%)
			Ineffective	3 (25%)
			Worsening	0
PSI	Prophylactic	18 (33.33%)	Effective (fully or in part)	14 (77.8%)
			Ineffective	4 (22.2%)
			Worsening	0

LSA: lysergic acid amide; LSD: lysergic acid diethylamide; PSI: psilocybin.

^aAlthough initially assumed to be an abortive agent, three patients reported a prophylactic effect: one in terms of a cluster delay, two in terms of bouts of delay.

^bOnly one patient experienced a sudden disappearance of pain after the drug infusion; the others only perceived the pain as more tolerable.

rate of illicit substance use for CH treatment as an aim of our study.

At the time of their first use of illicit drugs, most of the CH cases were chronic and drug resistant, and participants had a high medical consultation rate. The majority of participants had tried subcutaneous sumatriptan, O₂ therapy, and at least one prophylactic treatment, although dosing information is unknown. All the participants reported their dissatisfaction with conventional medical treatments, even though not all of them had tried all the first-line treatment options. More than 50% of the patients reported that they had never tried illicit substances for recreational purposes and that their first contact with such substances was in response to their CH. The fact that most of the patients decided to try an illicit drug without (or against) medical advice could mean that their dissatisfaction with prescribed treatments had translated into a dissatisfaction with headache specialists and medicine in general. Our results describe a discouraging scenario in which patients with CH, despite a high consultation rate, did not receive all the first-line treatments, and reported feeling abandoned by their physicians after learning of their illicit substance use. We have no data to interpret

these results, pending the physicians' version; however, it does highlight the problem of a physician-patient relationship that is interrupted just when the need for counseling is at its greatest.

From the questionnaire, we have identified six types of illicit drugs used by CH patients: cannabinoids, cocaine, heroin, LSD, LSA, and PSI. It was not the aim of this study to discuss the self-reported treatment response rates of these substances. However, we would like to highlight the fact that patients who reported a low efficacy of illicit drugs largely used them as abortive therapies (cannabinoids, heroin, cocaine), although these substances are strongly related to both analgesic effects (8) and the development of dependence (9). On the contrary, patients reported a significant prophylactic effect from hallucinogenic agents even if consumed only on to three times per year, usually at sub-hallucinogenic doses. These results enrich the debate about the nature of patients' interest in using illicit drugs for CH treatment and appear to contradict the notion that these drugs were used for recreational purposes. In other words, it appears that individuals were not trying to experience the psychotropic effects of these drugs, but were trying to evaluate their

effectiveness in terms of treatment of CH. Despite this, the problem of abuse/dependence on such substances remains a hot topic in this field. In fact, patients with CH are more prone to using illicit drugs for recreational purposes (2). Moreover, people with chronic migraines who overdose on medication are regarded as patients who have developed a substance abuse problem sustained by a genetic background (10–12).

The final, critical point regarding illicit drug consumption is related to the associated legal issues. The illegal nature of these substances can lead to potential judicial consequences that patients often underestimate. In Italy at the time of the survey, there was a very restrictive law regarding the use and possession of illicit substances, and cannabinoids had yet to be decriminalized. Moreover, the purchase of these substances may often finance organized crime and illicit drug trafficking.

There are certain limitations to the present study. The self-reported information collected regarding the

CH diagnosis of patients was not clinically corroborated by the authors. However, this study was designed in line with other surveys previously conducted on patients with CH (5–7). Furthermore, our data cannot estimate the effectiveness of illicit drugs as a treatment for CH; randomized controlled trials with well-titrated medications by certified laboratories are needed to provide definitive answers about the effectiveness of illicit agents for CH treatment.

In conclusion, some patients decided to use illicit drugs to treat their intractable CH. This option is usually selected based on recommendations from other CH patients obtained via the Internet, and coincides with the abandonment of conventional medical care. It is worrying that a patient would trust a stranger on the Internet rather than a well-known physician. This leads to several unanswered questions regarding the interactions of physicians with CH patients, and the approach taken to such discussions regarding illicit drug use.

Key findings

- Drug-resistant cluster headache (CH) is a clinical challenge for physicians and a cause of frustration for patients.
- Patients sometimes try alternative treatments, including illicit substances.
- Patients' choice to use illicit drugs is driven by their dissatisfaction with conventional treatments.
- There is much information about the use of illicit drugs as CH treatment available for anyone on the Internet.
- Patients seemed to underestimate the judicial consequences and had an overestimated confidence in the safety of such treatments.

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Conflict of interest

None declared.

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