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## Review Paper

# Access to treatment with controlled medicines rationale and recommendations for neutral, precise, and respectful language



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## ABSTRACT

The European Pain Federation EFIC, the International Association for Hospice and Palliative Care, International Doctors for Healthier Drug Policies, the Swiss Romandy College for Addiction Medicine, the Swiss Society of Addiction Medicine, and the World Federation for the Treatment of Opioid Dependence called on medical journals to ensure that authors always use terminology that is neutral, precise, and respectful in relation to the use of psychoactive substances. It has been shown that language can propagate stigma, and that stigma can prevent people from seeking help and influence the effectiveness of social and public-health policies. The focus of using appropriate terminology should extend to all patients who need controlled medicines, avoiding negative wording. A narrow focus on a few terms and medical communication only should be avoided. The appropriateness of terms is not absolute and indeed varies between cultures and regions and over time. For this reason, it is important that communities establish their own consensus of what is 'neutral', 'precise', and 'respectful'. We identified twenty-three problematic terms (most of them we suggest avoiding) and their possible alternatives. The use of appropriate language improves scientific quality of articles and increases chances that patients will receive the best treatment and that government policies on psychoactive substance policies will be rational.

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## Introduction

Recently, on behalf of their organizations, five authors from our author group, representing the European Pain Federation EFIC, the International Association for Hospice and Palliative Care, International Doctors for Healthier Drug Policies, the Swiss Romandy College for Addiction Medicine, the Swiss Society of Addiction Medicine, and the World Federation for the Treatment of Opioid Dependence called on medical journals world-wide (editors-in-chief, editors, and reviewers) to ensure that authors use neutral, precise, and respectful wording.<sup>1</sup>

The call, an opinion piece, was perforce brief, and we could not in detail describe the language that we consider appropriate. With this article, we provide additional inappropriate terms, explanation, and alternatives. We do so on a personal title.

## Similar calls in the past

This call was not the first for neutral, precise, and respectful wording regarding the use of psychoactive substances. In 2014, the Editorial Team of the journal *Substance Abuse* called on its authors, reviewers, and readers to use language that makes an appeal for respecting people ('people-first language'), focusing on the medical nature of substance use disorders and treatment, to promote the recovery process and to avoid perpetuating negative stereotypes and biases.<sup>2</sup> Ironically, they found that the denomination of their journal did not meet their own criteria, a problem that many journals and medical societies in this area will encounter. In 2015, the International Society of Addiction Journal Editors (ISAJE) published the ISAJE Terminology Statement, against the use of language that can stigmatize.<sup>3</sup> The Journal of Addiction Medicine adopted guidance for authors with respect to linguistic do's and don'ts.<sup>4</sup>

Over time, various authors have discussed the importance of 'person-first' language and other aspects of respectful terminology.<sup>5–10</sup> Yet, much of the language that continues to be used in relation to the use of psychoactive substances can propagate stigma intentionally and unintentionally: a mark of dishonor, disgrace, and difference that depersonalizes people and deprives them of their individual or personal qualities and personal identity.<sup>2</sup> Phillips and Shaw showed that individuals who use substances receive more stigma than individuals with obesity and smoking.<sup>11</sup> A meta-analysis showed that stigma has a small to moderate negative effect on help-seeking among people with mental illnesses.<sup>12</sup>

The rationale for banning inappropriate terms, such as pejorative or disrespectful words and descriptions is clearly established by Kelly, Dow, and Westerhoff and by Kelly and Westerhoff.<sup>13,14</sup> Their experimental and quasi-experimental survey studies showed that the use of certain terms (e.g. describing someone as a 'substance abuser') can induce implicit cognitive biases that perpetuate stigmatizing attitudes that may influence the effectiveness of our social and public-health policies for addressing them. In the case of substance use disorders,

this is of particular importance because these disorders are a major public-health concern.<sup>15</sup>

## More change is needed than you think

The sources we cited here focus almost entirely on people who use psychoactive substances and treatment of substance use disorders. However, we would argue that more treatments and more people are affected:

1. Terminology related to psychoactive substances affects treatment of all disorders and diseases that require availability and accessibility of controlled medicines, including opioids (for treatment of moderate and severe pain, dyspnea, and for opioid agonist treatment of opioid dependence), stimulants (in narcolepsy, Attention Deficit Disorder, and Attention Deficit Hyperactivity Disorder), and to a lesser extent, hypnotics and anxiolytics, antiepileptics, and emergency obstetrics.<sup>16</sup> Research by the World Health Organization (WHO) showed that 5.5 billion people (79.3% of the world population) live in countries where opioid analgesics are not readily available for those who need them.<sup>17,18</sup> There is only a limited number of countries where opioids are available for the treatment of substance use disorder.<sup>19</sup> Recently, China attempted to bring the anesthetic ketamine under international control in the United Nations (UN), which would have brought around two billion people in developing countries out of reach of anesthesia and thus, of surgery.<sup>20</sup>
2. When it comes to what type of terminology is inappropriate, most of the focus has been so far on the terms 'abuse' and 'misuse' and on terminology which is not 'patient-first' (as is shown by the sources referenced in the preceding section). However, we argue that there are many other terms which are not neutral and which do not describe substance use disorder as a disorder. This limits and impedes patient access to treatment.<sup>13,14</sup> It is also disrespectful toward people who use psychoactive substances, being stigmatizing, pejorative, or a combination of both.
3. When it comes to the question of who should change terminology, most of the focus so far has been on medical journals and healthcare professionals. We argue that the administration is equally important, including national governments, legislators, judiciary systems, and international organizations like the UN. Moreover, the terminology used by the press determines the terminology used and the views held by the general population, politicians, and civil servants.

The other authors agree with Kelly, when he argued that some of these terms may have 'potentially important implications for patients (e.g. stigma), treatment programs (e.g. access), and policy (e.g. appropriation of healthcare funding).<sup>10</sup> However, we would include more examples here, e.g. the refusal of pharmacological treatment to patients with pain, and people with substance use disorders being refused

methadone by courts and prison authorities. We believe this should be a medical decision; legal provisions which make it impossible to physicians to make the best evidence-based decisions for their patients must be avoided.

As previously discussed, various publications have shown that language influences patient access through the attitudes of healthcare professionals and through policies on psychoactive substances. The rationale of this being already sufficiently established, we will explore now a few linguistic aspects.

### Cultural, temporal, and geographical variation

The appropriateness of terms is not absolute. It is dependent on the perception of a word by the emitters and receptors of messages. This means that it can (and will) change over time; it can be perceived in different ways by different subpopulations. Subpopulations may be different groups within one local community but also speakers of the same language in different regions. For English, being spoken in so many parts of the world, the connotation of a word will not necessarily need to be the same everywhere. For example, there are subtle differences between English in the United Kingdom, North America, and India. Moreover, when assessing appropriate terminology in another language, the straightforward translation of an acceptable word in one language might result in a pejorative, stigmatizing, or disrespectful word in the other language.

As a result, when we provide a list of words to be avoided, and suitable alternatives, every linguistic community should check and discuss it. However, this should not be done without taking into account that many texts are used beyond the borders of communities. Scientific manuscripts are read worldwide; therefore, they need to contain language acceptable for professionals worldwide. On the other end of the spectrum, information leaflets are written by healthcare professionals but read by laymen locally. They do not need international acceptance but acceptance by the local target audience. More challenging may be policy documents, which affect the entire population at local, national, or even international levels and therefore, are likely to have a wide diversity of subpopulations and subcultures targeted.

This requires that language communities everywhere establish their own consensus of what is neutral, precise and respectful, and which words should not be used. This should be done with priority for the official UN languages (English, Arabic, Chinese, French, Spanish, and Russian). However, other language communities should not wait. Where there is as yet no consensus (and even when there is), authors and speakers should not stop discussing the consequences of what they say.

### Undesirable terminology

We identified a number of terms which are problematic when used in the medical domain with explanation on

problems and alternatives (Table 1). We also suggest some alternative terms that may be appropriate under certain circumstances only.

Using undefined or ill-defined terms is imprecise and affects the quality of science. We found that some people use definitions deviating from what has been agreed internationally, sometimes even opposite to these official definitions (e.g. defining ‘withdrawal’ or ‘tolerance’ as ‘dependence’). We decided to follow accepted international definitions, as we believe that not doing would be imprecise and would confound communication over frontiers.

Although we insist on most of the alternative terms in Table 1, for some we feel the debate is still open. Moreover, finding really good alternatives is not always easy and may require more discussion and creativity.

For example, the term ‘addiction’ has been criticized already in 1963 by the then Expert Committee on Addiction-Producing Drugs of the WHO.<sup>21</sup> At the time, the Committee considered it to be a confusing term. Yet, although WHO then changed the Committee’s name into ‘Expert Committee on Dependence-Producing Drugs’, the word ‘addiction’ has been persistent over time and even WHO continued to use it elsewhere. Quite recently, in 2012, the Committee stated again that ‘addiction’ is stigmatizing and pejorative.<sup>22</sup> These all raise the question whether words derived from a Latin verb which literally means ‘making someone the slave of someone else’, is it a good word for referring to a disorder or a person having a disorder? It is not part of international definitions and therefore, is it, aside from potentially being stigmatizing and pejorative, also imprecise?

Regarding the term ‘aberrant behavior’, we considered the alternatives ‘patient non-compliance’ and ‘patient non-adherence’. Broyles et al. argued that such alternatives may also sound judgmental or patronizing.<sup>2</sup> We decided not to recommend these alternatives either, as this type of term blames the patient, while we think that in most cases, the concept as such is wrong: often the details of a therapy may have been explained insufficiently or it may be even impossible to follow a therapy as prescribed. In reality, it actually is the combination of a specific patient with a specific level of feasibility of the proposed therapy (that might be complicated) and the accuracy and clarity of the instructions given by healthcare professionals. We are aware of pharmacotherapy schedules, which are almost impossible to be used as intended. This aside from the observation by Scholten and Henningfield, that when it relates to a comparison between the populations using opioid medicines and the population using any medicines, there is no difference in accuracy of following therapy between these two groups.<sup>23</sup> Finally, we decided upon the phrase ‘Using medication not as prescribed or intended’.

Related to the selection of a neutral, precise, and respectful vocabulary is the aspect of attitude. In this respect, it may be better to use ‘wrong’ terms while being obviously respectful toward people, than using nice words, while being clearly condescending or patronizing them. Part of such a respectful attitude is the recognition of a person’s agency.

Table 1 – Problematic terms, problems related to their use and their alternatives.		
Problematic terms	Problem	Alternative(s)
Aberrant behaviors	Pejorative, <sup>6</sup> judgmental	Using medication not as prescribed or intended See also in the text.
Abuse	Judgmental and ambiguous; <sup>24,25</sup> implying wilful misconduct; it negates the fact that substance use disorders are a medical condition <sup>26</sup>	Non-medical use or use In order to avoid too much repetition in a text, at first mention ‘non-medical use’ can be used, followed by ‘use’ at further occurrences. Note that ‘harmful use’, ‘hazardous use’, ‘recreational use’, and ‘compulsory use’ are overlapping with non-medical use but not identical to this. They can only be alternatives under circumstances. If used, these words should be used in a non-moralizing manner and well-defined, e.g. the context should make clear to whom the use is harmful and what type of harm is done. In case of using ‘recreational use’, this cannot be put on par with ‘non-medically’ automatically, as it depends on the substance and can be different for each individual user and even differ from one occasion of use to another.
Addict	Not person-first language (reducing the person to one characteristic), <sup>27</sup> pejorative and stigmatizing <sup>25</sup> under circumstances	Person with substance use disorder or person with dependence
Addiction	Pejorative and stigmatizing <sup>25</sup> under circumstances Addiction comes from Latin ‘addicere’: making someone the slave of someone. <sup>10</sup>	Substance use disorder (as defined in the Diagnostic and Statistical Manual of Mental Disorders; DSM-5) (preferred); dependence (as defined in International Classification of Diseases; ICD-10), dependence syndrome. Use of terms in other diagnostic systems is acceptable provided the terms are used as defined
Addictive substance	Not logical to use under circumstances (compare the previously mentioned)	A compound which might promote a substance use disorder; substance use disorder producing substance
Clean vs dirty (as a test outcome)	Stigmatizing, not describing the test result, <sup>3</sup> judgmental	Negative vs positive test result
Clean vs dirty (as a person) <sup>18</sup>	Extremely stigmatizing, judgmental, not approaching the person as any other patient would be referred to. Will reduce the person's self-esteem and self-efficacy	A person (not) using/using psychoactive substances non-medically
Criminal law (when referring to substance control legislation)	The preambles of the Single Convention on Narcotic Drugs and the UN Convention on Psychotropic Substances declare that the conventions have the ‘health and welfare of mankind’ as a primary objective. <sup>28,29</sup> Different from criminal law, which has as the objective to regulate prosecution of crimes (e.g. a murder – which would constitute a crime by everybody also without having a law on its punishment), drug law regulates availability of psychoactive substances. The method of prohibition chosen results in the creation of new crimes as a derivative ‘only’. Most national laws are the implementation of these two conventions and do not intend to create a crime primarily but do so as the result of regulation of health effects. <sup>28</sup>	Health law Note that this is related to the concept rather than to the terminology
Dependent or dependent person	Not person-first language (reducing the person to one characteristic)	A person with a substance use disorder
Detoxification	Misleading: simplistically representing the dependence treatment as the washing out of a substance	In therapy for cessation (or reduction) of psychoactive substance use; tapering (off); medically managed tapering from a psychoactive substance

Drug	Ambiguous language; in particular, when a controlled medicine is meant, the word interferes with the promotion of its availability <sup>28</sup>	Depending on the context: either medicine or psychoactive substance
Drug users	Not person-first language (reducing the person to one characteristic) <sup>9,30</sup> Also note that using psychoactive substances is not the same as being dependent on these substances	People who use psychoactive substances (or people who inject psychoactive substances, if applicable) Note that ‘people who use drugs’ and so forth, although in most contexts being clear, is also intrinsically ambiguous.
Drug control conventions	In order to avoid the use of the ambiguous word ‘drug’, referring to the conventions as ‘drug control conventions’ is not preferred. (These conventions do not control medicines)	Conventions for the control of psychoactive substances, or substance control conventions
‘The patient failed treatment...’	It is not the patient who failed, but the treatment	The treatment failed, or the treatment was not efficacious/effective <sup>4</sup>
Illicit substance	Misleading: it is not the substance itself that is illicit, but its production, sale, possession, or consumption in particular circumstances in a given jurisdiction	Controlled substance Note that “illicit substance use” can be correct terminology
Junkie, crackhead, speed freak, and so forth	Pejorative and stigmatizing	Person who uses psychoactive substances; person with substance use disorder (depending on the context)
Medication-assisted treatment	Misleading: misrepresenting the character of this treatment in which effective medicines are at the core <sup>30</sup>	Opioid agonist therapy (OAT), opioid agonist therapy for the treatment of substance use disorder, treatment. <sup>8</sup>
Misuse	Considered judgmental, although less judgmental than ‘abuse’ <sup>27</sup>	See above under ‘Abuse’
Narcotic	Archaic terminology to refer to a class of substances by an unimportant side-effect of only some members of the class. <sup>5</sup> Narcotic suggests the side-effect ‘sleep inducing’, but this is called today a ‘hypnotic’. Furthermore, it is hardly a side-effect of any substance in the Single Convention, and certainly not the main side-effect for opioids (which is constipation). Moreover, some substances under this convention are stimulants <sup>1</sup>	Psychoactive substance (or for specific cases: opioid, stimulant, opioid medicines, opioid analgesics, and so forth) The use of ‘narcotic’ is justified if it refers to the list of substances regulated by the Single Convention on Narcotic Drugs, but then, it is in the mere sense of a substance listed in a convention defining its contents as such and stripped off its meaning of ‘hypnotic’
Opiate	Not in line with chemical nomenclature rules <sup>5</sup> The suffix ‘-ate’ is reserved for salts and esters	Opioid (see the Glossary of WHO Guidelines Ensuring Balance in Controlled Substance Policies for the various meanings of the word ‘opioid’) <sup>28</sup>
Problem user <sup>10</sup>	Judgmental	Person with substance use disorder (preferred); person with dependence or patient
Physical dependence	Misleading: usually refers to the symptoms of withdrawal and tolerance, which do not constitute dependence according to the definition of dependence. Who says ‘physical dependence’ has to tell his audience simultaneously that this is not dependence. Contradictory as this is, it is not very likely that the audience will accept or even understand such a message. It is much easier to use ‘tolerance’ and ‘withdrawal’ and to explain that for dependence at least one of four other symptoms are necessary <sup>31,32</sup>	Withdrawal and/or tolerance
Substitution therapy or opioid substitution therapy (OST)	Misleading: gives the impression to politicians, civil servants, and other lay people that this therapy is replacing ‘street drugs’ with ‘state drugs’; and therefore, this language counteracts availability of therapy	Opioid agonist therapy (OAT), opioid agonist therapy for the treatment of substance use disorder, treatment. <sup>8</sup>
These terms should be avoided in our view, although some are acceptable in a special context (which is indicated if the case); an exception is “addiction”, which is, however, worthy of debate. Some alternatives are much longer than the original term and we encourage thinking of better and more concise alternatives.		

## Conclusion

The use of neutral, precise, and respectful language is related to the scientific quality of manuscripts. It increases chances that patients will receive the right treatment, and it also increases chances that politicians and administrators will take rational decisions related to psychoactive substance policies. For effective communication, the formal level needs to be in accordance with the semantic level, and language being part of this level, it is important both to be respectful and to write in a respectful non-stigmatizing way.

We recommend avoiding the terms in the left column of our table in scientific publications or documents by national and international governmental organizations. We also suggest not using these words in other contexts. We believe that these words do not convey respect for patients or people who use psychoactive substances. Neither do they improve attitudes among healthcare professionals, policy makers, and the public who acknowledge the right to appropriate treatment of pain patients, patients with a substance use disorder, and others who need controlled medicines. However, we do not claim that all terms are equally negative if used. This is related to our vision that there is cultural, geographical, and temporal variation in perception. What is important is that every writer and every speaker is aware of the effects of his or her words and commits to an appropriate lexicon that conveys the same dignity and respect we offer to patients not needing or using psychoactive substances.<sup>18</sup>

### How to change in the workplace

Many people have been using inappropriate terminology for years, perhaps since the beginning of their professional careers or even earlier. If this is the case, it is not easy to change now. It needs motivation, but we can make this easier by providing alternatives. The dynamics of change can also be helpful if everybody is working on appropriate terminology simultaneously: when one is the only person using 'new' terminology, one will feel uncomfortable in so doing. If, on the contrary, everybody is contributing to a change, one does not want to be left behind.

### Lives of people are at stake

Kelly, Saitz, and Wakeman pointed out that there is a tension between being clear and unambiguous and communicating in shorthand with more speed and efficiency, but the effort of modifying language is worth the effort in the recognition of equity and the resolution of prior stigmatization. In this case where the lives of a historically marginalized population are at stake, there is a need to sacrifice efficiency in favor of accuracy and the potential of minimizing the chances for further stigma and negative bias.<sup>18</sup>

### Transferring to other language communities

The Anglophone character of this article means that we confine our examples to terms in English. We cannot cover the hundreds of languages around the world for which this must also be done. These languages are used for communication between healthcare professionals and their patients and are also relevant for policy development. Many of them are used by the media (newspapers, radio, and television). For all these purposes, in order to communicate in a professional way, the choice of words needs to be neutral, precise, and respectful.

## Author statements

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