

## For most fully alcohol-attributable diagnoses in the ICD, the etiological specification should be removed

### *La CIE debería de eliminar la especificación etiológica en la mayoría de diagnósticos atribuibles al alcohol*

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The International Classification of Diseases (ICD) is the international standard for defining and reporting diseases and health conditions, with the purpose of providing a foundation for the identification of health statistics and trends globally, as well as evidence-based decision-making (World Health Organization, n.d.). There are more than 40 diseases which are 100% attributable to alcohol (Rehm et al., 2017) in the current versions of the ICD (10<sup>th</sup> revision [ICD-10] and 11<sup>th</sup> revision [ICD-11]) (World Health Organization, 2018a). The practice of specifying alcohol, alcoholic or alcohol-induced in the name of a disease in the ICD has been occurring since the 1920s. However, it is time to reconsider this practice for the majority of these disease and injury categories, with the exception of disorders due to use of alcohol (ICD-11: 6C40) or alcohol poisoning (ICD-11: NE61, PD00, PH50), as it often does not lead to a specific clinical intervention, but rather has a number of negative consequences. In this contribution, it is argued that the etiological specification should be removed from the names of most fully alcohol-attributable diagnoses in the ICD using

two specific examples to outline the consequences of this practice: alcoholic liver disease (ICD-11: DB94) and foetal alcohol syndrome (FAS; ICD-11: LD2F.00).

### Alcoholic liver disease

First, diagnoses of all disease categories with alcohol in the name are considerably underestimated in both the health-care system, as well as on death certificates. Consider the classic study of Puffer and Griffith (1967), which included data from 12 cities in ten countries, and compared data on death certificates with data from hospital records and interviews of attending physicians or family members. This led to more than a doubling of the number of deaths deemed to be due to alcoholic liver cirrhosis, with the majority of new cases having been recorded originally under other categories of cirrhosis, none of which referred to alcohol as the causal agent. This kind of underreporting has persisted in current times and is not restricted to alcoholic liver disease, but rather extends to other chronic diseases fully attributable to alcohol (see examples in Rehm, Hasan,

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Imtiaz & Neufeld, 2017). It has been demonstrated using various comparison standards, autopsies, clinical markers, interviews with family members, as well as indirect measures. One of the main reasons for underreporting is this: diagnoses with alcohol are associated with a high level of stigmatization, over and above the stigma of mental disorders (Schomerus et al., 2011). Heavy drinkers and people with alcohol use disorders are not only seen as responsible for their disorder, but are also thought to be aggressive and disruptive. This stigma may lead to heavy drinkers avoiding the health-care system and, ultimately, a failure to disclose their alcohol use (Probst, Manthey, Martinez & Rehm, 2015).

For the treatment of liver disease itself, most treatment interventions are the same irrespective of the etiology—that is to say, interventions for the liver do not necessarily differ, and alcohol use should always be assessed, minimized or avoided. Assessment of alcohol use can be done via modern biomarkers such as phosphatidylethanol (PEth) (Carvalho, Heilig, Perez, Probst & Rehm, 2019; Andresen-Streichert, Müller, Glahn, Skopp & Sterneck, 2018), thus avoiding potential underreporting as a result of stigmatization. The reason for assessing alcohol use and intervening when it is reported is that for people affected by liver cirrhosis, even relatively small amounts consumed regularly may lead to death (Fuster & Samet, 2018). Unfortunately, alcohol use is often not addressed when it is not considered to be the etiology of the disease. This is problematic, as a recent study of all French patients over a five-year period showed that 71.8% (95% confidence interval [CI]: 66.0% to 76.8%) of 17,669 liver-related complications, 67.4% (95% CI: 61.6% to 72.4%) of 1,599 liver transplantations, and 68.8% (95% CI: 63.4% to 73.5%) of 6,677 deaths in people with chronic hepatitis C virus infections were due to alcohol use, and a large part could have been avoided if alcohol use had been addressed (Schwarzinger, Baillot, Yazdanpanah, Rehm & Mallet, 2017). The above numbers may even be an underestimate for the reasons mentioned above: alcohol use is not regularly assessed and reported in French hospital settings, and disorders used to identify heavy alcohol use in this study were likely underreported. This reasoning is even true for the so-called non-alcoholic fatty liver disease (ICD-11: DB92), where alcohol use plays a role in worsening as well (Fuster & Samet, 2018).

Finally, the reliance on alcoholic liver disease as a category severely impedes the estimate of the true impact of alcohol, as people are classified based on their presumed original etiology, and not on the impact of alcohol as a risk factor. For example, an analysis that relied on the diagnosis of alcoholic liver cirrhosis to estimate the proportion of liver cirrhosis mortality and burden of disease attributable to alcohol (GBD 2016 Alcohol Collaborators, 2018) estimated about 50% lower mortality and 60% lower burden of disease than an analysis that used all liver cirrhosis and

estimated the contribution of alcohol via the usual epidemiological attributable fraction methodology in the World Health Organization Global Status Report (World Health Organization, 2018b). Furthermore, the differentiation of alcoholic vs. non-alcoholic liver disease is often made based on the reported alcohol intake of the patient. The threshold varies between 20-40 grams of pure ethanol per day; however, aside from the fact that most people are not able to report their alcohol intake accurately, or are simply being dishonest, this threshold seems arbitrary and does not consider the multifactorial etiology of liver diseases (Pimpin et al., 2018; Roerecke et al., 2019). Again, the use of biomarkers such as PEth would be advisable for both clinical practice and research.

This is not to say that alcohol is not one of the leading risk factors for liver diseases, but identifying an “alcoholic” liver disease ignores the contribution of other risk factors, and conversely, the contribution of alcohol is ignored in the so-called “non-alcoholic” liver diseases.

## Foetal alcohol syndrome

As with other fully alcohol-attributable diagnoses, individuals prenatally exposed to alcohol often feel judged by others, which prevents them, or their family members, from seeking diagnostic services and interventions that could contribute to an improved quality of life, in order to avoid being labeled with a stigmatizing diagnosis. Stigma is an important clinical risk factor as it is known to delay treatment-seeking, worsen course and outcome, reduce compliance, and to increase the risk of relapse, causing further disability, discrimination and isolation even in individuals who have accessed services (Shrivastava, Bureau, Rewari & Johnston, 2013). It is for this reason that women also tend to deny or underreport their alcohol use during pregnancy (Lange, Shield, Koren, Rehm & Popova, 2014), which ultimately leads to the misdiagnosis of FAS. The purpose of a classification system is to provide disorder categorizations that are independent (Lecrubier, 2008); however, the co-existence of FAS with other neurodevelopmental disorder diagnoses (such as, attention deficit hyperactivity disorder [ICD-11: 6A05]) appears to be the norm (Lange, Rehm, Anagnostou & Popova, 2018). In fact, it was recently found that children with foetal alcohol spectrum disorder, the umbrella term used to encompass a number of alcohol-related diagnoses including FAS, are neurodevelopmentally and behaviorally indistinguishable from children with other neurodevelopmental disorders (Lange, Shield, Rehm, Anagnostou & Popova, 2019). This finding is a demonstration of the insignificance of specifying alcohol as the cause of the neurodevelopmental impairments with respect to clinical practice, especially given that there is no evidence to support such differentiation with respect to treatment effectiveness (Premji, Benzie, Serrett & Hayden, 2007).

Prenatal alcohol exposure is associated with a wide range of symptoms and a diagnosis of FAS is not an indication of a specific set of those symptoms. Even worse, a diagnosis of FAS does not lead to an established treatment plan (Price & Miskelly, 2015), as there is no specific therapeutic strategy for FAS (Murawski, Moore, Thomas & Riley, 2015).

## Discussion

It is clear from the two examples presented above that specifying “alcohol” in the name of a disease has limited clinical relevance, and can even lead to delayed care and mistreatment. Such a specification can lead to inappropriate reporting, which has significant implications for research, public health policy, and health-care planning, especially given that, as all evidence indicates, conditions containing “alcohol” in their name will be underreported.

It can certainly be argued that the specification of alcohol in a disease name is necessary to maximize prevention efforts. In fact, the incidence and prevalence of a condition are indicators of the respective conditions’ public health burden and provide a basis for resource allocation for health care and prevention initiatives. However, if such estimates are flawed because they are based on a system that inherently leads to misdiagnosis, then it should be deduced that the system itself is flawed. Given that, as the international diagnostic classification standard for clinical and research purposes, maximizing prevention efforts is not the purpose of the ICD (World Health Organization, n.d.), and that other methodology exists to determine the correct incidence and prevalence of conditions that would not exist without the contribution of alcohol (Rehm et al., 2004), successful prevention initiatives are not contingent on specifying alcohol, alcoholic or alcohol-induced in the name of a disease in the ICD. Consider tobacco use as an example: prevention of tobacco-attributable disease burden was certainly possible without creating disease categories such as tobacco-induced lung cancer.

Further, one of the major aims for classifying patients as having one disorder or another is to link them with the best possible therapeutic intervention (Lecrubier, 2008). If the treatment approach does not differ from that of other conditions with the same symptomatology, whether idiopathic or not, then specifying alcohol in the name of such health conditions is simply not necessary.

One could argue that the root of the problem is stigmatization, and in fact, contrary to other mental disorders, stigmatization of harmful alcohol use and alcohol use disorders has not improved over the past couple decades (Schomerus, Matschinger & Angermeyer, 2014). As such, efforts are urgently needed to address the stigma surrounding fully alcohol-attributable conditions, and thus, in this day and age having disease names which promote stigmatization is unacceptable. We currently have a system that

results in inaccurate conclusions for clinical care, health policy and research with respect to most fully alcohol-attributable conditions, which can easily be fixed. Therefore, it is time for the ICD to remove the etiological specification of alcohol in disease names when it comes to diseases causally linked to alcohol.

## Conflict of interest

The authors have no conflicts of interest to declare.

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