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When the cause of death does not exist: time for the WHO to close the ICD classification gap for Medical Aid in Dying

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Summary

Medical aid in dying (MAID) is a highly controversial ethical issue in the global medical community. Unfortunately, the International Classification of Diseases (ICD) of the World Health Organization (WHO) lacks coding for MAID. Therefore, no robust data adequately monitors worldwide trends that include information on diseases and conditions underlying the patients' request for assisted dying ("MAID gap"). Countries with legalised MAID observe substantial increases in cases, and likely additional countries will allow MAID in the near future. Hence, we encourage the WHO to create specific ICD codes for MAID. According to internationally established practices, a revised classification would require separate MAID-codes for (1) assisted suicide and (2) voluntary active euthanasia including supplemental codings of diseases, clusters of symptoms and function-oriented categories. By addressing these concerns, the WHO could close the "MAID gap" with new codes providing urgently necessary insights to society, public health decision-makers and regulators on this comparatively new social and medical ethical phenomenon.

Search strategy and selection criteria **Data for this Viewpoint were identified by searches of MEDLINE, PubMed, and references from relevant articles using the search terms "Medical Aid in Dying", "Assisted Dying", "Assisted suicide", "Voluntary active euthanasia", "End of life decisions" and "Cause of death statistics". Only articles and sources published in English between 1997 and 2023 were included."**

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Keywords: **Medical aid in dying; Assisted dying; World Health Organization; ICD classification; Cause of death statistics**

Introduction

Over the past 20 years, the Western world has come to acknowledge the individual's autonomy of directing one's own death, especially in response to terminal illnesses or unbearable symptoms and functional limitations causing intolerable suffering.[1–5] In consequence, legalisation of medical aid in dying (MAID) continues to be one of the most highly controversial ethical issues of recent time in the global medical community[6–9] and enters the mainstream. Thus, an increasing number of countries, including Switzerland, the Netherlands, Belgium, Luxembourg, Spain, Portugal, Austria, Colombia, Canada, some US states (California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Washington state, Vermont and Washington D.C.), New Zealand and the six Australian states permit various forms of organised MAID (see Table 1).[14–16] Based on the populations of these countries and federal states, approximately 300 million persons worldwide have legal access to an applicable form of assisted dying.

Medical aid in dying – understanding the need to address the WHO's blind spot of the ICD classification system ("MAID gap")

Countries that have handled assisted dying cases for a greater length of time have observed marked increases in the annual number of cases over time, e.g.:

- Switzerland, the country with the longest history of legal MAID worldwide and its current form already in practice for about 35 years,[10–13] has experienced a doubling of recorded cases every 5 years since the

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Only a limited number of countries or federated states across the world have laws that allow various forms of Medical Aid in Dying (MAID).[a]
AS: Assisted suicide; doctors are permitted to prescribe lethal drugs for self-administration.
VAE: Voluntary active euthanasia; in addition to AS, doctors or health care professionals are permitted to also administer the lethal drug.

	Country/federal state (legal form: AS or VAE; year introduced)
Terminal Illness Requirement (TIR)	USA (AS): Oregon (1997), Washington state (2008), Montana (2009), Vermont (2013), California (2016), Colorado (2016), Washington D.C. (2016), Hawaii (2019), Maine (2019), New Jersey (2019), New Mexico (AS, 2021) New Zealand (VAE, 2021) Australia (VAE): Victoria (2019), Western Australia (2021), Tasmania (2022), Queensland (2023), South Australia (2023), New South Wales (2023)
Terminal Illness Requirement (TIR) as a key criterion when the regulation on MAID was initially introduced; TIR was removed in later revised regulations.	Switzerland (AS, 1942; in 2004, AS was for the first time part of the ethics protocol in the *Swiss Medical Association* Code of Professional Conduct in selected cases fulfilling the TIR; revised in 2018 and 2022)[b] Columbia (VAE, 1997; revised in 2021) Canada (VAE, 2016; revised in 2021)
No Terminal Illness Requirement.	Netherlands (VAE, 2001) Belgium (VAE, 2002) Luxembourg (VAE, 2009) Spain (VAE, 2021) Austria (AS, 2022) Portugal (AS, 2023)[c]

[a]In some countries such as Germany, France, and Italy, there are active discussions about implementing MAID. In Germany and Italy, Federal or Constitutional Courts declared that existing laws which up until now criminalized MAID in the national Criminal Codes are unconstitutional or incompatible with the Basic Law. In both countries, however, the parliaments have not yet passed laws regulating how MAID should be practiced in their countries. In April 2023, a citizen's convention on MAID was held in France, which voted 76% in favour of its legislation. As a consequence, President Macron has indicated the government will draft an end-of-life bill by Autumn 2023.

[b]According to the Article 115 of the Swiss Criminal Code which entered into force in 1942, AS is only illegal in cases where it is carried out "for selfish motives". The Swiss model of AS arose in the 1980s (the first documented case in 1985) with this background of a comparatively open legal regulation.[10-13] In 2004, the Swiss Academy of Medical Sciences (SAMS) stated for the first time in their guidelines regarding "End-of-life care" that a physician may, on the basis of a personal decision of conscience, assist in suicide if there is a serious disease that will lead to death in the foreseeable future. This terminal illness requirement was abrogated in the revised SAMS guidelines in 2018 and 2022.

[c]VAE is only allowed in cases where AS is impossible due to a physical incapacitation of the patient.

Table 1: **Current Medical Aid in Dying requirements around the world.**

turn of the millennium (1999, *n* = 63; 2020, *n* = 1251).[10]

- The Netherlands, where MAID has been permitted since 2001, cases increased relatively slowly during the first 5 years (from 1815 cases in 2003 to 2231 cases in 2008). However, the following 5 years (2009–2013) showed a 13–19% increase annually, resulting in 4829 cases in 2013. This steady growth continued into 2021, with 7666 MAID cases reported in that year.[17]
- Canada, the Federal Government passed legislation about MAID in 2016. Cases have increased tenfold within 6 years (2016, *n* = 1018; 2021, *n* = 10,064).[18]

Globally, cause of death statistics are compiled in accordance with the rules set by the *World Health Organization* (WHO), i.e., the diseases and conditions underlying death are coded based on the *International Statistical Classification of Diseases and Related Health Problems* (ICD; currently in use: the 10th version, ICD-10).[19] In countries with various forms of legally assisted dying, it has long been understood that the ICD classification does not provide a separate and dedicated code for MAID. This leads to the fact that this comparatively new social and medical ethical phenomenon is not adequately reflected in the national cause of death statistics. To date, this issue goes unresolved. Obviously, only a revision of the ICD classification system would close this "MAID gap".

Against this suggestion, one might argue that the WHO is not necessarily responsible for including these causes of death in the ICD classification, especially if they are only possible to use in a few countries due to confined regulations. However, we counter this argument with two main reasons:

1. Data from countries where MAID is permitted shows an impressive and rapid increase of MAID after legalisation, emerging from being a marginal phenomenon to develop into a substantial and non-negligible proportion of a country's deaths. Currently, patients choosing MAID account for 1.8% of all deaths in Switzerland,[10] 3.3% in Canada,[18] and even 4.5% in the Netherlands.[17] At this time, evidence suggests that these numbers will continue to rise.

The "MAID gap" in the ICD classification currently affects only those few countries where MAID is legally permitted and practiced. However, in all Western countries and also in those US states where MAID is not yet legal, there are continuing, intense, and often contentious debates to varying degrees about this difficult topic. We assume, with reasonable certainty, that additional countries will alter or adjust their laws during the next few years to also allow for defined forms of MAID (plans are currently advancing in Germany, Italy and France, for

example). Thus, an implementation of ICD codes which would adequately record MAID would probably vastly expand beyond its current reach.

2. In those countries that already allow MAID today, there are national registers with these cases. In an international comparison, however, there are considerable differences in the quality of reporting between each country. The annual reports from the Dutch "Regional Euthanasia Review Committees"[17] are exemplary. In contrast, in Switzerland, which does not have a national registry for MAID cases, the Federal Statistical Office publishes only a marginal dataset of annual cases since they have only access to the death certificates completed by the forensic medical doctor or a public health officer, who investigated and certified the circumstances of the death, but do not have access to the medical reports of the physicians who prescribed the lethal medication which include more detailed information on the diseases or the conditions underlying the wish to die. The introduction of a worldwide uniform ICD classification for MAID would be a valuable step to standardize the data quality for international comparisons for this increasingly important medical ethical issue.

Proponents of assisted dying see its legalisation as an achievement of a modern society which assigns a high value to the individual's autonomy. In contrast, opponents of MAID argue that these practices are fundamentally inconsistent with the physician's professional role of healing, managing pain and alleviation of suffering. This role does not allow to intentionally inflict death, the latter being incontestable and non-negotiable cornerstones of medical practice.[6,7] Therefore, assisted dying violates the essence of medicine and irreversibly undermines the patient's and society's trust in the moral integrity of the medical profession. As a matter of fact, even "moderate proponents of MAID" fear that after the legalisation of assisted dying, safeguards put in place for these practices will be bypassed, leading to uncontrolled case volumes. These proponents advocate the principle that MAID should be reserved to terminally ill patients and/or to those that suffer unbearable and uncontrollable severe symptoms. They surmise that MAID due to accumulation of old age complaints or due to psychiatric disorders or dementia goes too far. With this in mind, the "slippery slope argument" was introduced: this describes circumstances in which an innovation, once created, generates its own potentially unstoppable momentum to grow beyond its initial confines.[20,21]

There are no universally accepted answers to the key questions concerning MAID. Which procedures and medical indications are acceptable for legal assisted dying? What value is set upon the individual's freedom of will and choice? On the other hand, when should access to MAID be restricted in order to protect people from their own impulses?

Furthermore, one might fear that a "culture of euthanasia" may pressure vulnerable elderly in need of care to use MAID, especially in societies that value autonomy, self-responsibility, economically driven, with a strong disdain for any sort of dependence upon the state or welfare system. Thus, individuals may feel that they are not serving any meaningful purpose for society anymore and might feel increasingly pressured to relieve their families and their surrounding environment of the burden of their existence ("*duty to die*").[22–24] In addition, those having succumbed to more adversity in life, they may be more vulnerable to end their life, with societal influences, mutual responsibility, and a culture of kindness that may have compensated for losses.[25] Such persons in a correspondingly similar socialisation and environment may become the next groups to slide down the slippery slope. Dealing with these questions will be one of the most pressing tasks of Western societies in coming decades.

Compiling causes of death data is not an end in itself. Information on mortality and causes of death occasionally identifies new patterns of diseases or their handling that demand public health-level attention and to enable decision-makers to implement appropriate measures. The "MAID gap" in the ICD classification entails that data in the international cause of death statistics are unreliable for one of the most current challenges and debates in medical ethics: how do we, both society and the medical profession, deal with persons who ask for MAID?

Obviously, it would be presumptuous to claim that these central social and medical ethical questions could be answered by improvements to document cause of death statistics alone. However, an ICD classification that reliably traces and depicts the MAID phenomenon will certainly be a valuable part of providing comparable and more reliable international data for crucial upcoming developments. We firmly believe that the WHO has an obligation to develop a foundational framework for closing this gap.

Considerations for closing the "MAID gap"

The epidemiologists of the Swiss Federal Statistical Office have striven to remedy the "MAID gap" by expanding an existing ICD code for suicide by poisoning (code X61 which is used for "Intentional self-poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs"). In 2009 they created their own supplementary code for MAID (X61.8).[26] This approach fits Switzerland where only assisted suicide (AS) is legal. However, this code extension cannot be easily adopted worldwide, since some countries, currently the Benelux countries, Spain, Canada, Colombia, New Zealand, and the Australian states (see Table 1) also allow for voluntary active euthanasia (VAE), in addition to AS. The differences

between AS and VAE are significant, especially from a medical ethical perspective. In AS, the role of the physician primarily consists of prescribing a lethal dose of one or more MAID drug. The critical point is that those, who wish to end their life on their own free will, must carry out the final act of the procedure themselves.[27] By contrast, in VAE, doctors or health-care professionals may also administer the lethal drug. Those opposing VAE claim that precisely this active role in the process of dying violate the fundamental principles of medicine. This has a significant potential to permanently damage public and patient confidence in the role of the medical profession.[7] Because of this special medical ethical balancing act, it may be critical for the WHO to consider the two distinct forms of MAID (AS and VAE) and to create two different ICD codes for assisted dying.

Far more complex than the mere recording of MAID case numbers in cause of death statistics, however, is the recording of the circumstances and illnesses underlying voluntary hastened deaths. This can be accomplished relatively easily if the valid jurisdiction allows MAID only in persons suffering from a terminal illness that are expected to die naturally in the immediate future. This is usually defined as death occurring in no more than 6 months.[15] This terminal illness requirement is an indispensable criterion of legislation in New Zealand as well as in the Australian and the US states that permit assisted dying. MAID cases could be coded in these situations using ICD-based cause of death statistics with a "MAID code" yet to be created in combination with an established code of a corresponding underlying disease. This approach would also be in accordance with the WHO classification rules which stipulate that the cause of death should be the disease that is at the beginning of the course leading to death. In this sense, MAID is usually the last resort taken at the end of a critical disease.[28]

In some countries, however, the regulations about MAID go beyond the terminal illness requirement. As demonstrated in Table 1, countries such as the Netherlands, Belgium, Luxembourg, Spain, Portugal and Austria have introduced legal regulations regarding MAID that also include symptom-based conditions, i.e., a state of intolerable suffering as an acceptable indication for assisted dying. Switzerland (in 2018), Colombia and Canada (both in 2021) have adjusted their guidelines and laws from the initial regulation on MAID limited to terminal illness as the only justification for MAID. The criteria defined in Canada's 2021 "Act to amend the Criminal Code (medical assistance in dying)" to grant access to legal MAID to people willing to die are found in almost identical wordings also in the legislative texts of other countries that have adopted similarly liberal laws ("diagnosed with a grievous and irremediable medical condition", "serious and incurable illness, disease or disability", "advanced state of irreversible decline in capability", "experiencing enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable").[18] It can be expected that countries currently discussing legalisation of MAID will adopt comparable rulings in the future.

In light of this broad legislation with MAID, symptom-oriented motivations for the wish to die challenge the current scope of the ICD classification. In cases of an accumulation of old age complaints, chronic pain syndromes (e.g., severe rheumatic diseases, polyneuropathy), long-term treatment-resistant psychiatric disorders, or diseases that manifest themselves with neurologically caused severe limitations of mobility (e.g., Parkinson's disease, multiple sclerosis, stroke-related paralysis, traumatic spinal cord injuries), cognition, or sensory disabilities such as blindness, the ICD classification might be able to depict the motivational background of the person willing to die. The above-mentioned diseases usually represent severe, immobilising and invalidating chronic conditions. For the patients concerned, this means a high level of suffering, usually without any hope of an improvement in their situation. However, these conditions are not immediate causes of death in the accurate definition recorded as the cause of death on the death certificate.[29] However, functional aspects of these diseases may be less transparent in the ICD classification system and an assessment by using the International Classification of Function (ICF)[30] may be warranted to more fully depict the situation of an individual who chose MAID.

Outstanding questions

In medicine (including cause of death statistics), the phenomenon where some conditions and events are perceived by the affected individuals to be so serious that they justify the wish to die is neither new nor uncommon. Conventional suicides also involve personal reasons and motivations for a wish to die and acting upon them. The unique aspect of MAID is that a doctor acknowledges and recognises these motivations, writes a prescription for a lethal drug, and in cases of VAE, even administers the fatal substance. In particular, symptom- and function-oriented MAID cases due to conditions that do not lead to natural death in the foreseeable future, are central to the topic in medical ethical discussions worldwide. In order to be able to follow future developments and trends in MAID, the motivational backgrounds for these cases should be recorded as reliably and accurately as possible. Thus, if the WHO creates the ICD classification for AS and VAE, additional "MAID sub-codes" should further enhance data collection to accurately code the cause of death. As recently proposed, these sub-codes would have to contain easy-to-handle symptom- and function-oriented categories, e.g., MAID due to: multi-morbidity

We suggest an extension of the classification from chapter 23 ("External causes of morbidity and mortality") with a new code that exclusively describes the phenomenon of "Medical aid in dying".	
Subheading: Medical Aid in Dying PM1: Assisted Suicide. PM2: Voluntary Active Euthanasia.	
Comment: (1) Medical aid in dying is considered as the circumstance in which a doctor prescribes a patient wishing to die one or more lethal substance or makes these available with the object of enabling the patient to die. In Assisted Suicide, the physical control of administering the drug is in the hands of the patient, i.e., the patients wishing to die must themselves carry out the last, decisive act of the procedure that will cause death. In contrast, in Voluntary Active Euthanasia, the physician or health-care professionals also administers the lethal drug. (2) The underlying disease or condition recorded with the ICD-11 coding was the main reason for the wish to die. If the wish to die was not based on tangible illnesses leading to a natural death in the foreseeable future, but rather on other diseases or symptom-oriented complaints, additional codes (PM1.1-4; PM2.1-4) can be used.	
PM1.0 / PM2.0	The underlying ICD-coded disease was the main reason for the wish to die.
	Comment: This code includes, for example, the most common group of indications for MAID today, namely cancer, e.g., the case of a woman who decides to have AS at a late stage of breast cancer will be coded PM1.0 or PM2.0 and 2C61 (Invasive carcinoma of the breast).
PM1.1 / PM2.1	Medical Aid in Dying due to multimorbidity
	Comment: Multimorbidity also includes the accumulation of old age complaints. In this case, it does not matter which of the usually several existing age-related diseases and conditions is additionally coded as underlying disease.
PM1.2 / PM2.2	Medical Aid in Dying due to severe neurologic-related conditions.
	Comment: In this case, the underlying neurologic disease that was critical to the desire to die must be coded, e.g., for Parkinson's disease: PM1.0 or PM2.0 and 8A00.0. This code includes cases in which neurodegenerative diseases (e.g., Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis) were the main reason for the desire for death. Cases in which dementia was the underlying condition of the desire for death are excluded (→ PM1.4 or PM2.4). Cases in which severe neurological limitations such as blindness and paralysis (tetraplegia) led to MAID are also included. Similarly, this category also includes patients for whom the consequences of a stroke were the determining factor to choose MAID. In a symptom-based system, it makes much more sense to remove these cases from the category of "cardiovascular diseases," in which they are currently still classified. When the consequences of a stroke lead to MAID, there is virtually always a clinical picture of severe and irreversible immobility and paralysis. This clinical picture then corresponds far more to those of the other neurologically related diseases summarized in this chapter than to those of other cardiovascular diseases, e.g., heart failure.
PM1.3 / PM2.3	Medical Aid in Dying due to chronic pain.
PM1.4 / PM2.4	Medical Aid in Dying due to mental disorders or dementia.
PM1.Z / PM2.Z	Medical Aid in Dying, unspecified.

Table 2: Proposal for an extended ICD-11 classification in cases with Medical Aid in Dying (MAID) including symptom-oriented categories; adapted from.[29]

(including factors such as severe gait disturbance, urinary and/or stool incontinence), severe neurologic-related conditions, chronic pain, and mental disorders or dementia (see Table 2).[29] The cause of death statistics would then be able to reflect the actual reasons for the vast majority of these deaths.

Contributors

UG, RW, SM, ARS and EB have directly conceptualised the article theme, searched and critically reviewed the relevant literature and wrote the article. All authors read and approved the final version of the manuscript.

Declaration of interests

The authors declare no competing interests.

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