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International Statistical Classification of Diseases and Related Health Problems (ICD-11): from its origin to its use in digital systems

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Abstract *The International Statistical Classification of Diseases and Related Health Problems (ICD) allows the systematization of health statistics around the world. This study describes the origin, functionalities, forms of construction and updating of the CID, through a qualitative, exploratory and descriptive study focusing on document analysis, considering official documents and technological tools. Since its creation, the ICD has been revised and published, reflecting its connection to advances in health, science and society. Such reviews were accompanied by many studies, debates and consensus. The current version of the ICD, called ICD-11, in addition to traditional content revisions, has been transformed to better adapt to the digital world. This new version has been available in Portuguese since February 2024 and its implementation is in process in Brazil – a fact that requires preparation from all operators of the Unified Health System.*
Keywords *International Statistical Classification of Diseases; Public health; e-Health*

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Introduction

Classifications typically bring together perceptions of reality, its goals and phenomena into systematically organized groups with the goal of facilitating both the perception of the same reality and the exchange of knowledge and communication in a more agile and standardized way[1].

In the context of health, there are various classification tools for clinical purposes, including the International Statistical Classification of Diseases and Related Health Problems (ICD), which groups similar or related health conditions according to a hierarchy and is used as a basis for representing individual health diagnoses and conditions, which in turn are used to systematize health trends and statistics in local, regional, national and international areas[2].

Since its inception, the ICD has been revised and published regularly to reflect advances in health, science, and society. For example, the new edition of ICD-11 has sparked several debates, including those related to gender diversity and gender development processes, in particular the code for "gender contradictions in childhood"[3]; eating and feeding disorders[4]; and the implementation of the dimensional approach to psychopathology[5].

ICD-11 has been developed with the aim of adapting to the digital age, the information, and knowledge society, with various changes and adaptations[1]. Each distinct concept in ICD-11 has been given a unique and unchangeable identifier (URL), which allows a health information system to locate reliable information on a topic in any of the languages available on the World Health Organization (WHO) platform, facilitating cross-border healthcare. To help URLs identify the numbers and entities contained in ICD-11, the WHO has developed a set of application programming interfaces, or RESTful Web resources, that allow any developer to integrate ICD-11 into various information systems. In addition, this resource makes it possible to find the appropriate code for a condition or disease in ICD-10 or previous revisions in the Index Volume[6].

Understanding the importance of the ICD for public health and humanity, this research aimed to describe the origin, functionalities, ways of constructing and updating the ICD, emphasizing the technological transformations that occurred in the 11th edition (ICD-11), which has been available in Portuguese since February 2024, to be implemented in Brazil[7].

Methodology

A qualitative, exploratory and descriptive study was carried out with a focus on document analysis, using as reference criteria[8,9] such as the authenticity and reliability of the author(s) and key concepts. To this end, official documents and technological reference tools for understanding the ICD in its different versions were considered. Scientific research illustrating the use of the ICD was added to the study. Therefore, this research did not involve the collection of primary data[10] and may introduce subjectivities inherent in the discourse of the research subjects who, through this documentary and qualitative analysis, have constructed a discourse that is approximate and susceptible to questioning, revision and future improvement[11].

Documentary analysis is not arbitrary. It is justified when the researcher wishes to systematize or disseminate a concept, a research object or a methodological approach more widely[12], as is the case with this study, which is focused on understanding the ICD and its revisions.

Results

The analysis followed the chronology of the ICD editions up to its current version (ICD-11).

The beginnings of the ICD

The history of the ICD goes back to England in the 16th century. The first statistical study of disease, or in this case, the analysis of mortality by cause, is generally attributed to the Englishman John Graunt, known as the first epidemiologist. This study, published in the journal "Natural and Political Observation Made Upon the Bills of Mortality", examined mortality in London using data recorded in parishes and considering several variables, including sex, age, origin, and cause[13]. Graunt listed 83 causes of death, some of which were aetiological, others concerned pathogenesis, while the remainder related to the circumstances leading to death or the signs and symptoms that preceded it[14]. Internationally, there has been considerable interest in using the same classification system because of the need to compare causes of death between countries and between regions or areas within a given country. For this reason, many attempts at systematization have been made, especially since the second half of the 19th century.

In proposing a classification of deaths, the epidemiologist Willam Farr noted that diseases could be classified in different ways, which served both statistical purposes and the purpose of studying causes of death. His project was strongly influenced by the Swedish botanist Carolus Linnaeus and his hierarchical classifications applied to botany and zoology. In this sense, Farr proposed a classification that is recognized as the structural basis of the current ICD[15].

In 1853, during the First International Statistical Congress held in the city of Brussels, the participants appointed William Farr and the Swiss doctor Marc d'Espine to present a uniform nomenclature of causes of death applicable to all countries[15,16].

In 1855, the Second International Statistical Congress was held in Paris, where Farr and d'Espine presented separate lists based on different axes of classification[15,16]. The classification proposed by Farr included 5 classes, namely Class 1 - Epidemic, endemic, and contagious diseases; Class 2 - Constitutional diseases; Class 3 - Localized diseases; Class 4 - Developmental diseases; and Class 5 - Violent diseases or deaths. This classification is considered to be the matrix for the current ICD.

Marc d'Espine presented a list that grouped diseases according to their nature (hematic, herpetic, etc.), but his work was not widely accepted. For this reason, the Congress adopted a list of 138 headings, essentially maintaining the structure proposed by Farr, but incorporating some of d'Espine's suggestions. Subsequently, the Congresses of 1864, 1874, 1880 and 1886 revised and updated this list[15].

In 1891, in Viana, the newly created International Statistical Institute, successor to the International Statistical Congress, established a committee to prepare a new classification of causes of death. This committee was chaired by French statistician Jacques Bertillon, who developed a classification of causes of death that became known as "Bertillon's Classification of Causes of Death"[15,17].

In 1893, after several attempts to create an international classification, Bertillon's classification received general acceptance and was adopted by several countries and cities and is considered the precursor to the ICD[14,15]. To date, the ICD has been revised 11 times, as described in Table 1.

The International List of Causes of Death was first revised in Paris in August 1900. Delegates from 26 countries attended. As a result of this revision, a detailed classification of causes of death consisting of 179 groups and an abbreviated classification consisting of 35 groups were approved[14,15]. A second meeting took place in 1909. This revision increased the number of conditions to 319. In this version, there was already a basic stratification of conditions, represented by a number and, if there were subcategories, by capital letters. In the third edition, published in 1920, the list of conditions was reduced to 315. The structuring scheme became more heterogeneous. Subgroups are defined by lowercase letters and subcategories by numbers. The fourth edition, published in 1929, contained 331 conditions. The stratification scheme of the list follows the pattern established in previous revisions. The fifth revision, published in 1938, contained 487 conditions. The revisions from the first list (1900) to the fifth (1938) were designated by the French government. Until the fifth revision, only diseases that were considered causes of death were included[19].

In the Americas, the International List of Causes of Death was first used by the physician Jesus E. Monjarás in the construction of mortality statistics for the city of San Luiz de Potosi, Mexico[20,21]. In 1898, the American Public Health Association recommended the adoption of this classification by registrars in the United States, Mexico, and Canada[15]. According to Laurenti, in the State of São Paulo, Bertillon's classification was used by the body that compiled mortality statistics as early as the first decade of the 20th century[14].

Bertillon was the promoter of the International Nomenclature of Causes of Death and the ratifications of 1900, 1909, and 1920, which were developed under his direction. As Secretary General of the International Conference, he submitted the provisional revision of 1920 to more than 500 technicians for their opinion. However, he died in 192215. In 1923, a meeting was held in France to appoint M. Michel Huber as Bertillon's successor.

The Hygiene Organization of the League of Nations also showed interest in health statistics and appointed a Commission of Statistical Experts to study the classification of diseases and causes of death and other questions in the field of medical statistics[22]. To systematize the work of the two bodies, a mixed commission was created, with equal representation from the WHO and the International Statistical Institute. This committee developed proposals for the

Table 1. Revisions to the International Classification of Diseases.

Reviews	Year	Years of use	Diseases	External causes	Assist. reasons Health
1ª Review	1900	1900-1909	157	22	
2ª Review	1909	1910-1920	157	32	
3ª Review	1920	1921-1929	166	39	
4ª Review	1929	1930-1938	164	36	
5ª Review	1938	1939-1948	164	36	
6ª Review	1948	1949-1957	769	153	88
7ª Review	1955	1958-1967	800	153	88
8ª Review	1965	1968-1978	858	182	48
9ª Review	1975	1975-1992	909	192	77
10ª Review	1989	1993-2020	1.575	373	82
11ª Review	2019	2022	55,000	not located	not located

Sources: Adapted from Laurenti[14] and Lancet[18] and updated by the authors.

fourth and fifth revisions of the International List of Causes of Death[15,23,24].

The internationalization of the ICD

The Sixth Revision was adopted in Paris in 1948. On this occasion, the French government, in collaboration with WHO, was the secretary. Both played a key role in ensuring compliance with the agreement reached by the governments participating in the International Health Conference of 194615.

From the sixth revision onwards, the WHO assumed responsibility for the so-called "International Classification of Diseases" and its successive revisions25. With the advent of the ICD-6, in addition to causes of death, all diseases, injuries, and symptoms were included, as well as some consultation reasons that were not strictly considered "diseases"26. It also established international rules for the selection of the basic cause of death and encouraged the implementation of a broad program of worldwide cooperation in vital and health statistics. This included the formation of specialized national commissions to coordinate statistical work in the country and to act as liaison between WHO and national statistical services. WHO recommended that deaths by country in 1949 or 1950 should be coded according to the Detailed List of Causes of Death of the Fifth Revision, and that double tabulations of these data should be published in such a way as to indicate the changes resulting from the application of the new revision[27].

In 1955, the International Conference for the Seventh Revision (ICD-7) was held in Paris under the auspices of the WHO. At that time, only essential changes were made, corrections of errors and inconsistencies[15] and the inclusion of "fetal death" and "live birth"28. This facilitated international consensus on the meaning of "stillbirth" as a synonym for the term "late fetal death", which is the death of a fetus at 28 weeks or more of gestation. In addition, it allowed the registration and tabulation of fetal deaths as "early," "intermediate," or "late," using the same gestational ages for live births. WHO recommended that the term "stillbirth" be used as a synonym for the term "late fetal death" so that countries compiling stillbirth statistics could use it.

In 1965, the International Conference for the Eighth Revision of the ICD was held at the Palais des Nations in Geneva. On this occasion, the 36 Member States and one Associate Member participated in the Conference, which covered topics ranging from the presentation of the structure of the ICD to national and international events related to health statistics[15].

Some countries, particularly those with morbidity statistics, requested that the classification be much more focused on these uses throughout the ICD-8 preparation process[14]. The eighth revision of the ICD entered into force on January 1, 1968, with changes to the explanatory notes. It also approved the inclusion of a detailed list of three-digit categories and allowed for four-digit subcategories[15].

In 1975, the International Conference for the Ninth Revision of the ICD (ICD-9) was held in Geneva under the auspices of the WHO. Delegations from 46 Member States attended. The conference adopted a program with topics ranging from the presentation of the proposal for the ninth revision to the proposal for formalization and training in the use of the ICD-929.

ICD-9 is the result of a decade of work culminating in the Ninth Revision Conference held in Geneva in 1975[30]. This version introduced several innovations and adaptations, the most notable of which are the following:

- *Conventions for the use of signs in the Tabular List* (brackets, parentheses, and colons);
- *Dual diagnosis classification* - Implementation of two codes (cross (ɪ) and asterisk (*)) for certain diagnoses;
- *Function of Code E* - Corresponds to an auxiliary classification used to code external factors associated with morbid infections;
- *Gaps in code-number systems* - Certain code numbers were not used in ICD-9, which created gaps in the number system;
- *Inclusion of the glossary of mental disorders, categories related to Dentistry, Stomatology, Oncology, and Ophthalmology*[29].

Preparations for the Tenth Revision began in 1983 in Geneva at a meeting chaired by the WHO Director-General. The first meeting resulted in a plan of action, which established special meetings, including those of the Committee of Experts on the Classification of Diseases in 1984 and 198731.

In 1989, WHO convened the International Conference for the Tenth Revision in Geneva. The Conference was attended by representatives of the WHO Regional Offices, the United Nations, the International Labor Organization, the Council for International Organizations of Medical Sciences, and twelve other nongovernmental organizations, as well as delegates from 43 Member States[31].

ICD-10 introduced many innovations, including its division into 3 volumes. Volume 1 contains the main classifications, the special tabulation lists for mortality and morbidity, and the definitions and standards relating to the classifications; Volume 2 contains the guidelines for use; and Volume 3 contains the alphabetical index[31]. The main ICD (a three- and four-digit classification) contained in the three volumes could not accommodate all the additional information and should remain accessible and relevant to conventional users[32]. However, with the idea of a "family" of classifications of diseases and health-related topics, the WHO included a volume, published separately from the main ICD, with additional information to be used as needed.

Up to the Ninth Revision, the ICD presented a list of three-digit codes divided into up to ten four-digit subcategories. ICD-10 uses an alphanumeric code to identify the various conditions, with a letter in the first position, followed by up to four numeric characters, with the fourth character accompanied by a decimal point. The three-digit codes divide the major diagnostic categories into categories based on disease, site, or symptoms. All WHO Member States use these three-digit codes as the legal basis for coding causes of death. The fourth digit is used for more precise definitions[33].

In ICD-10, the descriptive sections of the diagnostic categories have been greatly expanded to include a detailed clinical description[34]. Another important aspect of ICD-10 is the assignment of multiple diagnoses34, as it establishes a classification of psychiatric syndromes rather than diseases. This means that the patient will receive diagnoses until certain criteria are met. This does not necessarily mean that the patient has all the illnesses, but the assignment of concomitant psychopathological conditions is essential from a therapeutic and prognostic perspective[34].

The advent of ICD-11

There was a gap of about 30 years between ICD-10 and ICD-11, which broke the premise of continuous updating35. ICD-11 was adopted in 2019 at the seventy-second session of the World Health Assembly. The main reasons that led to the need for the eleventh update of the ICD were: the need for scientific updating; the need for a structural change to digital format due to the incorporation of digital environments in all health care settings and work environments; the possibility of links to other terminology systems; the need to improve the reproducibility of important clinical details of conditions to improve usability; and the need for detailed guidance for ICD users[36].

ICD-11 features a revised chapter structure and indexing system consisting of more than 55,000 entities. In addition to diseases, the eleventh update includes injuries, disorders, external causes, symptoms and signs, substances, drugs, devices, anatomy, histopathology,

severity, and more than 120,000 clinical terms, with new categories and updated classification schemes[36].

ICD-11 now contains 26 chapters and two supplementary sections. New to ICD-10 are chapters 3 (diseases of the blood and blood-forming organs), 4 (diseases of the immune system), 7 (sleep-wake disorders), 17 (conditions related to sexual health), 26 (conditions of traditional medicine), V (supplementary section for functional assessment) and X (extension codes), the latter of which will be used exclusively for post-coordination purposes[1].

ICD-11 is being developed against the backdrop of an unprecedented reality for society, as never before in human history has there been such widespread global integration. This has only been made possible by the advent of computerized communication systems and the ability to access information almost instantaneously. To adapt to this highly integrated reality, ICD-11 was developed with the aim of reducing reporting errors, covering cataloged information, and improving usability[36].

To make registration and consultation more practical, the current version is completely digital, reducing the expected reporting errors and facilitating the consolidation and dissemination of the new version. ICD-11 brings changes in content, new tools, and changes in presentation formats. Among the changes, the biggest advance is the acceptance of user suggestions through the platform created for the revision. It also includes a tool to assess implementation in the field (ICD-Fit), with analytical resources that allow the platform to be continually updated. Suggestions for revising concepts and codes are evaluated by advisory groups and, if relevant, implemented[36].

ICD-11 offers significant improvements over the previous version, including: Updated clinical knowledge; current concepts of primary care; revision of the human immunodeficiency virus section; inclusion of all diseases considered rare; inclusion of burnout syndrome, which is now classified as an occupational disease; addition of disorders caused by electronic games to the conditions that can lead to addiction; disorders that are part of the autistic spectrum have been grouped into a single diagnosis (autism spectrum disorder); Stroke has been moved from the circulatory to the neurological chapter; gender discordance, previously considered a "mental health" condition, has been added to Chapter 17; a new Chapter 26 has been added to correspond to the specific section on traditional medicine; and the format of codes has been changed37.

Among the updates made to ICD-11, the implementation of the dimensional approach to psychopathology stands out5 . This approach made it possible to include different types of child development disorders in the same category, as well as to graduate the degrees of involvement of autism spectrum disorders, similar to the diagnosis and statistics of mental disorders.

The addition of the chapter "Eating and Feeding Disorders" to ICD-11 separates eating disorders that involve behavioral disturbances that are not related to weight and body shape, such as eating inedible things or deliberately regurgitating food4. It also expands the clinical utility of the ICD by increasing the number of eating diagnoses and reducing the number of subsyndromal diagnoses or those classified as unspecified eating disorders.

As mentioned above, another significant change was the modification of the concept of gender identity disorder, which left the chapter on mental disorders[38,39]. In ICD-11, this disorder has been included as a "gender incongruence" condition in Chapter 17 (conditions related to sexual health). The self-designation, or the way in which a person wishes to be identified as transgender, transsexual, transvestite, man or woman, is essential to guarantee autonomy and mental health, a distinction from the legal effects of labeling their lives in diagnostic categories that enclose these experiences in pathologizing categories and associate them with illnesses.

Challenges for implementing ICD-11 in Brazil

As for the implementation of ICD-11 in Brazil, one of the first challenges already overcome was the translation into Portuguese1. The translation process began in March 2021 with the creation of the Technical Advisory Committee for the Management of the Family of International Classifications, called CTA BR-FIC, by the Department of Epidemiological Analysis and Surveillance of No communicable Diseases (DAENT) of the Secretariat of Surveillance and Environment (SVSA) of the Ministry of Health. The Federal University of Minas Gerais (UFMG) has been invited by the CTA BR-FIC to translate the ICD-11 into Portuguese, and will start this work in August 2021, with the

support of the Pan American Health Organization (PAHO)[7]. Finally, on February 14, 2024, PAHO made an official announcement about the launch of ICD-11 in Portuguese, which is available in its entirety at: https://icd.who.int/browse/2024-01/mms/pt.

About training for the use of ICD-11 in Brazil, PAHO's Virtual Campus for Public Health has made available a 25-hour self-study course for training professionals and health system stakeholders. This course is available in Portuguese, English, and Spanish and is free of charge40. Similarly, the Federal University of Goiás (UFG), in partnership with the Ministry of Health, has made available a distance-learning course on the use of health terminology, including ICD-11, for the training of health professionals in Brazil in simple language, with virtual classes and exercises[41].

Final Considerations

In short, it was clear that the International List of Causes of Death was created in 1893 because of the need to compare causes of death by area or region of a given country, and especially between countries. Since its inception, the International Schedule of Death Causes has been revised and published periodically to reflect advances in health, science and society. However, since the sixth revision, the International List of Causes of Death has been called the International Classification of Diseases, which is currently in its 11th revision.

The process of creating the ICD is quite complex, requiring many studies, debates, and meetings. The need to revise the ICD is mainly due to advances in the field of health, the emergence of new diseases and new terms and concepts, the need for scientific updating; the need to exclude/update codes, constant technological advances, but it is also the result of social struggles and cultural changes. It has also been observed that the major changes from one revision to the next are much more than just the inclusion and exclusion of diseases. Changes in the ICD bring a new perspective on human life, on health conditions, and on the very concepts of health and disease that are so much debated in the field of public health.

Finally, throughout its history, the various updates of the ICD have had an impact not only on patients and statistics, but also on implementation and use through computerized systems in digital format. It can be seen that several studies reinforce the importance of education and training of health professionals in the proper use of the ICD1,[42,43,44,45]. It is hoped that this article will help to involve and motivate more stakeholders in the study and research of disease classification.

Collaborators

Evaldo Aguiar Andrade and Maria Cristiane Barbosa Galvão participated in all stages of the conception and writing of the article.

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