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Incorrect and Sex-Inconsistent Mapping of Disorders: Identification of Sex Biases in the ICD-10, ICD-11 and SNOMED CT and How to Work Around Them

Nina HAFFER[a,b,1] and Sylvia THUN[a,b]
[a] *Berlin Institute of Health at Charité – Universitatsmedizin Berlin, Germany*
[b] *Charité – University Medicine Berlin, Germany*
ORCiD ID: Nina Haffer https://orcid.org/0000-0002-9541-2811, Sylvia Thun https://orcid.org/0000-0002-3346-6806

Abstract. In the international classifications ICD-10-WHO and ICD-11-WHO, many sex-specific diseases have incomplete coding. It is possible to further enhance semantic interoperability using SNOMED CT additionally to ICD. Part of the analysis of semantic interoperability of diagnoses in the ICD are Sexual Dysfunctions, Postpartum Depression, Sexual Assault, Premenstrual Tension Syndrome and Premenstrual Dysphoric Disorder, Female Genital Mutilation and Cutting, Gender Incongruence and Disorders of Breast. Labeling biases have been identified in all diagnoses, either in SNOMED CT or ICD. For mental disorders associated with pregnancy, gender incongruence and sexual violence the use of the GPS of SNOMED CT can help enhance semantic interoperability additionally to ICD.

Keywords. Sex bias, gender medicine, semantic interoperability, ICD-10-WHO, ICD-11-WHO, SNOMED CT

1. Introduction

Historically, medical research and practice have predominantly focused on the male body, leading to a systemic neglect of the unique physiological and psychological aspects of female biology [1,2]. To close the sex data gap, it is necessary to generate structured data. Within the standardization of the data, perpetuating error embedded in the definition of the standard being used, could e.g. hinder automated analyses using algorithms and artificial intelligence of large datasets [3-5]. So-called labeling biases creep into structured data collection regarding the use of code systems and terminologies. International licenses are required for the full use of the ontology Systematized Nomenclature for Medicine - Clinical Terms (SNOMED CT). However, the standardization organization SNOMED International has developed a Global Patient Set (GPS), which is available license-free [6]. And can therefore be used internationally. The following analysis reveals whether and to what extent SNOMED CT, International Classification of Diseases International Edition 10 (ICD-10) and ICD-11 developed by

[1] Corresponding Author: Nina Haffer; E-mail: nina.haffer@charite.de.

the World Health Organisation (WHO) contain sex biases. The aims of the analysis are 1. to deduce sex biases that arise in the treatment and due to data gaps to their continuation in the ICD versions and 2. to formulate a recommendation for the coding of medical concepts in cases where sex biases have been identified.

2. Methods

In this paper, we analyze sex biases in the ICD – the previously used 10th revision and the newly introduced 11th revision [4,5]. In addition to the ICD, the ontology SNOMED CT is also considered as an additional coding mechanism. In the first step, relevant ICD codes from the international editions are filtered. Both ICD-10 and ICD-11 are examined for completeness of content and differences between the new and old version are identified. In the second step, the license-free GPS of the SNOMED CT ontology is mapped to the relevant ICD codes. We examine whether the additional use of SNOMED CT can ensure greater semantic interoperability of the coding.

2.1. Identification of sex-inconsistent ICD-10 and ICD-11 codes

To analyze the coding, we filter out relevant diagnosis codes in both ICD versions. For this purpose, a consultation of 12 doctors (7), midwives (2) and nursing staff (3) is conducted as part of the analysis. Furthermore, the PubMed search terms *"sex bias AND diagnosis"*, *"disorder AND (ICD-10 OR ICD-11) AND (sex OR gender)"* and *"gender medicine"* identify sex-inconsistent diagnosis and treatment choices of illnesses. Also, the reproductive organs that differentiate the sexes are considered: the assumption is that if the disease is overlooked due to the still-present gender data gap with less existing data on female physiology than the male body, is usually associated with only one sex, although both sexes can be affected, or a disease manifests itself differently in both sexes, this may also be reflected in the diagnosis code.

2.2. Comparison of findings with the GPS of SNOMED CT

The ICD codes are then appended with associated SNOMED CT codes by mapping thematically relevant codes to the identified ICD codes. By comparing the possibilities of coding the respective diagnosis, we analyze whether the addition of SNOMED CT codes increases the coding accuracy and where semantically interoperable representation of clinical concepts is currently unobtainable.

3. Results

The following groups of disorders have been identified through consultation with experts and by literature search as prone to underrepresentation of sex-specific attributions: sexual dysfunctions [7], mental disorders associated with pregnancy, premenstrual syndrome (PMS), premenstrual tension syndrome (PMT) and premenstrual dysphoric disorder (PMDD), female genital mutilation and cutting (FGM/C), gender incongruence [8], and benign disorders of breast. The situation of sexual assault is also included.

Table 1. Identified group of disorders with the associated ICD-10/ICD-11 codes (International Editions).

Group of Disorders	Proposed ICD-11	ICD-10
Sexual Dysfunction	HA0x	F52.-
Mental Disorders associated with Pregnancy	6E2x	F53.-
PMS, PMT, PMDD	GA34.4, MF33	N94.3
FGM/C	GC51	-
Gender Incongruence	HA6x	F64.x
Disorders of Breast	GB2x	N64.x
Sexual Assault	PE1Y/XE6U2	-

SNOMED CT codes that come into question for the description of sexual dysfunctions (see Table 2) and mental disorders associated with pregnancy (see Table 3) are picked for showing for exemplary purposes.

Table 2. Comparison of code systems with codes related to sexual dysfunction regarding sexual arousal and ejaculation.

ICD-10	ICD-11	GPS SNOMED CT
F52.2 Failure of genital response F52.3 Orgasmic dysfunction F52.4 Premature ejaculation	HA01 Sexual arousal dysfunctions HA01.0 Female sexual arousal dysfunction HA01.1 Male erectile dysfunction HA03 Ejaculatory dysfunctions	5413009 | Abnormal male sexual function (finding) | 82195006 | Normal male sexual function (finding) | 28154007 | Abnormal female sexual function (finding) | 50633001 | Normal female sexual function (finding) | 74007000 | Sexual arousal disorder (disorder) | 44912006 | Clitoral erection (finding) | 60704006 | Penile erection (finding) 40335009 | Ejaculation (observable entity)|

Table 3. Comparison of all code systems with codes related to mental disorders associated with pregnancy

ICD-10	ICD-11	GPS SNOMED CT
F53.- Mental and behavioural disorders associated with the puerperium, not elsewhere classified	6E2x Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium	58703003 | Postpartum depression (disorder) | 18260003 | Postpartum psychosis (disorder) | 1269101009 | Maternal disorder during antenatal and/or intrapartum and/or postpartum period (disorder) | 424474002 | Difficulty coping with postpartum changes (finding) | 704294006 | At increased risk for depressed mood during postpartum period (finding) | 704678007 | Depressed mood with postpartum onset (finding) | 1269553009 | At increased risk for perinatal disorder (finding) | 1269562006 | At increased risk for postpartum disorder (finding) |

4. Discussion

The weaknesses of the ICD-10 and ICD-11 are caused by a lack of differentiation between male and female as well as differentiations between male and female that are superfluous. The breakdown of sexual arousal dysfunctions in the new ICD-11 into female (HA01.0) and male (HA01.1) categories is unambiguous in its function. "Arousal" being associated with females and "erectile" with males is insufficient. A clitoris can be erect and there is an associated code for clitoral erection in SNOMED CT

(see Table 2). The SNOMED CT concept of ejaculation (see Table 2) is ontologically subordinated to male sexual function and male reproductive function. Though female ejaculation is not associated with a disorder or dysfunction as its existence has not been substantiated for long [10], its unambiguous coding or a male-unassociated coding of ejaculation is necessary.

With ICD-11, it is now possible to refer to a depression or anxiety disorder via newly introduced post-coordination for mental disorders associated with pregnancy with the use of several codes. For syntactic interoperability with Fast Healthcare Interoperability Resources, it is often only possible to use one code for one specific data element, so either a code from the 6E2x group or the coding of unipolar depression or anxiety disorder would have to be used per data element. In SNOMED CT, on the other hand, postpartum depression and postpartum psychosis and symptoms related to these diseases can be coded using just one code (see Table 3). Antenatal complaints can be included via SNOMED CT for a more detailed description of peripartum diseases. Around one fifth of all US women are victims of sexual violence [11]. In the new ICD-11 version, it is possible to record sexual violence by post-coordinating the codes "PE1Y: Other specified type of assault by contact with person, animal or plant" and "XE6U2: Context of assault, rape or attempted rape". 27 codes in SNOMED CT GPS relating to sexual violence allow a unique description of the course of the crime and whether it is the rape of a woman, a man or a child. Transsexuality (F64.0) has been deleted as a disorder in the ICD-11 due to discrimination against people with a trans* identity [16]. In SNOMED CT, transsexuality is not a disease but defined as characteristics that can also further differentiate whether the person is a male-to-female trans*person or a female-to-male trans*person and whether the person has been surgically transgendered. Nevertheless, many gender*queer terms have not yet been added to the database [12]. Premenstrual disorders are now divided into three categories: PMS, PMT, and PMDD. While only the code N94.3 is possible for coding PMT in ICD-10, coding PMDD (GA34.41) is also possible with ICD-11. Both PMS complaints and PMT can be coded with ICD-11, as well as in SNOMED CT. Many changes have also been made for FGM/C in the ICD-11 and summarized under the disease group GC51. These are not part of the SNOMED CT GPS, although 200 million women worldwide are affected [13]. The labeling bias in this disorder group is visible in its code description. Classifications of FGM/C, proposed by WHO, refer to 'total removal of the clitoris'. The clitoris is not totally removed but the clitoral glans [14]. A female association is made in the description of the disorder group GB20 Benign breast disease, although men can also be affected, lipomas being the most common benign breast diseases among men [15]. Lipomas can alternatively be coded for men under 2E80.0 Lipoma. To eliminate difficulties in each of the terminologies, cross-language mappings between ICD and SNOMED CT ought to be further advanced [16].

5. Conclusions

In the ICD-10 and ICD-11, sex-specific diseases have incomplete or incorrect coding. The terminology database of SNOMED CT is larger than the ICD classifications' - there are more codes available for representation of clinical findings, disorders and clinically relevant events. For mental disorders associated with pregnancy, gender incongruence and sexual violence the use of the GPS of SNOMED CT enhances semantic interoperability additionally to ICD. For the coding of FGM/C and benign disorders of breast the definitions within the ICD terminology are to be changed.

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