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“Nothing About Us Without Us”: The Case for User Warrant in the ICD-11

Abstract

The 11th edition of the International Statistical Classification of Diseases and Related Health Problems (henceforth known as the ICD-11) will come into effect January 1st, 2022 and includes major revisions to the language used to describe gender identity. The classification uses scientific and literary warrants for revisions, but noticeably does not involve the transgender (used interchangeably with trans) community in order to gather their recommendations on what would be considered proper terminology and narratives. This paper uses transgender medicine as a case study for the use of user warrant within medical classification and knowledge organization.

1.0 Introduction and Background

The ICD is the global standard for data and vocabulary to assist in diagnosing health problems (*WHO/Europe brief – transgender health in the context of ICD-11*). Its purpose is to be “the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions” in order to effectively store, retrieve, and analyze health information; compare health information between hospitals, regions, etc; and make data comparisons across time periods in the same location (*International Statistical Classification of Diseases and Related Health Problems (ICD)*). This classification tool is used in various ways, including monitoring the prevalence of diseases and causes of death, tracking and analyzing external causes of illnesses, and recording rare diseases among other uses (*International Statistical Classification of Diseases and Related Health Problems (ICD)*).

The revisions that will be implemented with the ICD-11 in 2022 largely focus on the sexual health and gender identity categories. Terms such as “transsexualism” and “gender identity disorder of children” will be replaced with “gender incongruence of childhood”, “gender incongruence of adolescence or adulthood”, and “gender incongruence, unspecified” (*WHO/Europe brief – transgender health in the context of ICD-11*). The largest impact this change brings is the moving of “gender incongruence” from the “mental health and behavioural disorders” section to the conditions relating to “sexual health” with the projected aim of ensuring transgender individuals seeking gender-affirming medical care are able to obtain adequate access.

2.0 Transgender Medicine within the ICD-11

The ICD-11 is “based on clinical input, research, and epidemiology” (*International Statistical Classification of Diseases and Related Health Problems (ICD)*). Currently, the World Health Organization (WHO) uses a Joint Task Force

(JTF) to provide advice for ICD revisions based on scientific research (*Groups that were involved in ICD-11 Revision Process*). Members of the JTF include medical professionals and statisticians from different institutions, including universities, medical institutions, and government organizations (*ICD-11-MMS Joint Task Force (JTF) 2018, 2018*), making scientific and literary warrants the basis for the ICD. However, a cursory glance at the members' descriptions show that these professionals do not specifically work with transgender patients nor are any transgender advocacy groups involved with the revisions. These clinicians and medical professionals may have transgender patients and even advocate for equitability in medicine, but the lack of transgender-centered care means they may miss the nuances of medical transitioning and transgender culture.

These missed nuances are prevalent within the new descriptions of the revised categories as much of it stems from the 'Wrong Body Narrative' (WBN), "the associated tales of moving from one gender category to another to solve the 'problem' of being born in the wrong body" (Hughes, 2018, 181). The narrative describes a disconnect between the body and mind (or gender identity) (Hughes, 2018, 182) that can be shown through certain stories or actions (e.g. wanting to play with cars instead of dolls as a child). WBN is often utilized by transgender people in order to gain access to certain medical procedures (Hughes, 2018, 185), but many trans people reject the notion as it does not align with their journey through gender exploration and discovery. The narrative serves as a box, rather than a playing field, for how trans bodies are conceptualized, lived in, and normalized (Hughes, 2018, 181), and fails to consider the cultural, familial, and geographic aspects of transition. A transgender man who grew up in a family of mechanics, for example, may not believe WBN describes his situation because it was expected of him to enjoy the "masculine" activity of fixing cars.

The "gender incongruence" categories lean into this narrative in order to more easily define trans individuals' gender dysphoria experience. "Gender incongruence of childhood" is marked by a disparity between a pre-pubertal child's assigned gender and experienced or expressed gender (World Health Organization, 2018). Part of this disparity includes "a strong desire to be a different gender than the assigned sex; a strong dislike on the child's part of his or her sexual anatomy or anticipated secondary sex characteristics and/or a strong desire for the primary and/or anticipated secondary sex characteristics that match the experienced gender; and make-believe or fantasy play, toys, games, or activities and playmates that are typical of the experienced gender rather than the assigned sex" (World Health Organization, 2018). The description for "Gender incongruence of adolescents and adults" similarly states that it is categorized by "characterised by a marked and persistent incongruence between an individual's experienced gender and the assigned sex" (World Health Organization, 2018). With both these descriptions, there is a focus on a disconnect between the identity and body and a resulting anguish with the development of the body. However, many trans people

do not feel this type of disconnect at an early age or even at all. In *Trans: A Memoir*, Juliet Jacques (2016) states that the WBN “had never quite spoken to me” (75) and instead felt “not trapped in the wrong body but trapped in the wrong society” (305). Within the medical classification of transgender people, the focus is on the individual’s perceptions of feeling different than the societal standard, which many trans people reject, rather than the ways in which society pushes away and dismisses trans people.

3.0 The Case for User Warrant

As scholars have demonstrated through their work, classification of peoples and groups, and the warrants used to define them, has long term impacts on them, such as how they are classified (and humanized) in other classification systems and how they are represented and treated in government policy (Olsen, 2002, 169-170; Roberto, 2021, 87; Bowker & Star, 2008, 195-225). In particular, literary warrant is limited as terminology in some areas, including gender studies, are rapidly changing and inconsistently applied, resulting in the justification of using outdated and offensive terminology (Olsen, 2000, pp. 57-58). Scientific warrant works in tandem with literary warrant as “the use of literary warrant is de facto consultation with subject experts; if the terms used in the documents are used for the subjects and the authors of the documents are assumed to be expert over that which they write, then expert opinion is reflected in literary warrant” (Hoerman & Furniss, 2000). User warrant is important to incorporate as it allows transgender people to define themselves since scientific and literary warrants often lack the capacity.

Trans people, as a group, do not have set terminology that encompasses everyone in the community, as KR Roberto’s survey results (Roberto, 2021, 110-124) and Claire McDonald’s Instagram data collection (McDonald, 2020, 291-292) demonstrates. Both scholars have found that trans people define themselves with a wide variety of terms, including transgender, transexual, trans man, nonbinary, etc. This research can further indicate that there is no set narrative each person prescribes by. They often use their own language to describe their gender and experiences and, similar to using WBN in order to gain access to transition needs, use certain terms ‘they disliked or never used otherwise in order to explain their genders in ways that allowed non-trans people to grasp the basic principles; examples of this reluctant language include ‘transgender,’ ‘MTF [or FTM],’ and ‘born female [or male]’” (Roberto, 2021, 126-127).

The ICD-11 proves to be a prime case for the use of user warrant, in addition to scientific and expert warrants, when classifying medical information as it may change the descriptions and classification of transgender medical terminology in order to better reflect the transgender community’s varied transition journey. Transgender people currently are not allowed to have the agency to define their medical transition experiences, but it is necessary to allow them to do so. There is no set terminology that

defines the trans community and every transition is unique in its process and reasoning. The current classification excludes a significant portion of the community in its focus on the WBN. While trans people have historically used that narrative to gain access to medical procedures, they should not have to lie in order to obtain life saving medicine and surgery. Furthermore, this narrative may influence clinicians' perceptions of trans people and their medical needs as it sets up the expectation of what procedures a trans person should have to go through in order to "really" be the gender they are, even if it is not desired, through the implication that a person will want or need to "fix" the "wrong body" they are in. A lack of desire for any one of these procedures, whether because of personal preference, finances, or health risks, could lead to the denial of desired medical procedures, which in turn can lead to the inability to change government documents to reflect a transgender person's true gender. The use of user warrant would help better reflect other portions of the trans community who do not subscribe to the WBN and create a more inclusive and easily accessible approach to medical transitioning.

4.0 Future Research

The new revisions to the ICD in the 11th edition requires further investigation to determine its impact. Reclassification and new descriptions of transgender medicine within the ICD similarly would impact policy regarding transition related medical services as well as ease of access. Research can be conducted to analyze the impact of the revisions on government policy, particularly in a time where numerous anti-trans bills targeting trans health are being presented in legislation throughout the USA; gender marker change policy, as many of these policies point to a vague "transition related" surgery as a requirement; health insurance coverage policies; and clinicians' perspectives on their transgender patients, their transition, and how easily trans people are able to obtain their desired procedures as a result.

5.0 Conclusion

Transgender individuals often face a personal and unique journey when medically transitioning. The language they use to describe themselves and their journey varies based on individual preference as the community is not monolithic. Because of this, the ICD faces the difficult task of classifying individuals who may not fit their description or even wholly reject it. The inclusion of transgender voices and opinions through the use of user warrant on revisions relating to transgender medicine may more accurately define how large portions of the community view themselves and medical journey. This would more broadly encompass others within the trans community whose experiences do not align with the WBN, giving more agency to the community within the health fields. With future research, it may also show to greatly improve clinician perspectives on trans patients, improving transgender patient-provider relationships,

and more trans-accepting, clearer policies within government and health insurance coverage.

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