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Gender Harmony: A Case for Nursing Informatics

Karen L. COURTNEY [a,1], Kelly S. DAVISON[a], Mikayla HUNTER[b], Alexander WATSON[b], and Jess CRAWFORD[b]
[a] *University of Victoria, British Columbia, Canada*
[b] *University of Manitoba, Manitoba, Canada*
ORCiD ID: Karen Courtney https://orcid.org/0000-0001-9326-116X, Kelly Davison https://orcid.org/0000-0002-1965-4691, Mikayla Hunter https://orcid.org/0000-0001-9661-1479, Alexander Watson https://orcid.org/0009-0000-5401-6970 ,
Jess Crawford https://orcid.org/0000-0002-8864-6425,

Abstract. The design of digital health information systems around a conflated gender/sex binary contributes to health inequities. Lack of specific information that supports affirming communication lead to inappropriate care, disrespectful encounters with healthcare staff, and avoidance of health services by clients who have been harmed by misgendering, deadnaming and being outed. The HL7 International Gender Harmony Model (HL7 GHM) supports the design, implementation and use of DHIS that enable affirming clinical interactions and care. This case study will demonstrate how applying the HL7 GHM can address the harms reported in a recently published account of one patient in Canada.

Keywords. Health information standards, Nursing Informatics, health equity, health information systems, gender, sexual and gender minorities, HL7

1. Introduction

Outdated gender, sex and sexual orientation (GSSO) information practices in digital health information systems (DHISs) lead to clinical harm and perpetuates health inequities through inappropriate care, disrespectful encounters, and client avoidance of health services [1-7]. More specifically, the collection, use, sharing and reporting of incomplete, poorly defined and poor-quality representations of a person's gender expression and anatomy leads to misgendering, deadnaming and increases the risk that clinicians will 'out' their clients in healthcare settings. Conflation of sex/gender in DHISs leads to assumptions about a client's anatomy and affects prevention, diagnosis, and patient care.

Most existing DHISs use a single sex/gender field. Use of a single field conflates sex and gender as one data element although sex and gender are distinct concepts [6]. Additionally, in many DHISs, the only accepted value for the field is binary (male or female) [8]. This poses many challenges for safe and inclusive care for people who are not represented by a binary construct of sex and/or gender and creates institutional bias

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[1] Corresponding Author: Karen Courtney, School of Health Information Science, University of Victoria, PO Box 1700 STN CSC, Victoria, BC Canada V8W 2Y2 email: court009@uvic.ca.

in the form of cisheteronormativity because it is so commonly and routinely collected and exchanged for administrative as well as clinical purposes [6, 8, 9].

Administratively, health organizations use sex/gender information as a form of identification for billing purposes. In clinical practice, sex/gender information has been the basis for making assumptions about a patient's anatomy such as reproductive organs and hormones, which are then used for preventive care (i.e., screening or radiological shielding), interpretation of diagnostic tests, and care planning, to name a few.

The presence of a single sex/gender data field with binary value options is inadequate for safe and equitable clinical practice because it incorrectly assumes that sex and corresponding anatomy are unchanging over the human life span. Further, provision of respectful care requires accurate gender information [10]. Gender is part of one's identity and may or may not reflect one's birth assigned sex. Accurate information about one's gender helps to advance affirming care such as preventing calling patients by the wrong name and avoiding misgendering through use of incorrect personal pronouns.

Existing international health information exchange standards, which promote consistent representation of healthcare concepts and interoperability between systems and processes, are the foundation for data fields within DHISs. Changing the design of sex and gender information within DHISs requires modernizing international health information exchange standards. Informaticists, standards experts and clinicians are engaged with international standards development organizations in the work of separating sex/gender information into different fields for administrative and clinical purposes.

2. Health Level Seven Gender Harmony Model (HL7 GHM)

Health Level Seven (HL7) is a health information exchange standard. HL7 healthcare messaging standards have been widely adopted for the sharing of clinical, demographic, visit, and provider information between DHISs. The HL7 GHM supports the design and development of healthcare information systems and cultures that enable safe and affirming care for all people [11]. Further, the GHM is a structural intervention designed to address preventable harms in healthcare posed by incomplete or inaccurate GSSO information and the binary representation and conflation of gender and sex. The HL7 GHM includes several relevant data elements to advance affirming care with patients: Name to Use, Gender Identity, and Pronouns; and Sex Parameters for Clinical Use. The Recorded Sex or Gender data element was included in the GHM to capture data from legacy information systems with a single sex/gender field.

2.1. Name to Use

Patients may have a number of names they go by including nicknames, language-specific names, or names to affirm ones gender, which may vary in different contexts and change overtime [11, 12]. The GHM data element "Name to Use" is the name that a person wishes to be used in healthcare interactions. Where "Name to Use" is situated with a person's legal name, "Name to Use" should be displayed more prominently as a cue to clinicians.

2.2. Gender Identity

Gender is a social concept and, as such, is complex, including aspects such as gender expression, lived gender, felt gender, and gender identity. Gender identity (a person's sense of being a man, woman, both, neither, transgender, or something else) is distinct from one's gender expression and sex assigned at birth [11]. Gender identity is fluid, can change over time and is context dependent. The GHM data element, "Gender Identity" is intended to be used in clinical records to support affirming care.

2.3. Pronouns

Pronouns are linguistic tools used to refer to someone instead of using their name. Patients may use one, multiple, or no pronouns. Pronoun use may change overtime or in different contexts. Pronouns should not be assumed because neither gender identity, gender expression, nor sex determine a person's pronouns. Thus, the only means to determine someone's pronouns is by asking. The GHM data element "Pronouns" supports affirming care by providing the information that clinicians need to avoid misgendering a person.

2.4. Sex Parameter for Clinical Use

As part of the recent GHM, a separate field "Sex Parameter for Clinical Use" has been created. This data element allows clinicians to specify crucial contextual information that needs to be included with an order or a test result. This field will link relevant data from anatomical inventories and other artefacts to provide the necessary context for assumption-free preventive screening and other clinical decisions. Anatomical inventories will allow for patient care to be individualized, which will improve the quality of information available for research and policymaking.

2.5. Recorded Sex or Gender

As organizations may replace DHISs at different time intervals, the "Recorded Sex or Gender" element was created to reflect ambiguity of data that originated in legacy systems with a single sex/gender field. This field allows for the retention of historical data and interoperability between health information systems and other external information systems such as vital statistics, which may require legislative action to change. It is important to recognize that gender identity or sex cannot be assumed based on "Recorded Sex or Gender" and this administrative data element should not be used for clinical decision making.

3. Case Study

Key aspects and elements of the HL7 GHM were applied to a recently published account of care by a transgender person and demonstrate how patient harms can be avoided [13]. The case describes a transgender man's experience accessing medical care in the Emergency Department (ED). Throughout, Alexander reports deadnaming, inappropriate clinical care, and incorrect pronoun use. By implementing the HL7 GHM as a proactive intervention to promote competent care, experiences such as the one reported can be prevented.

During his clinical encounter in the ED, Alexander describes how he provided his Name to Use to hospital staff. Alexander experienced consistent deadnaming, based on the information that was present in his health card despite repeatedly correcting staff. "Name to Use" should be available to record Alexander's correct name and display it more prominently on clinical documentation, prompting clinical staff to use the patient's name.

Immediately upon attending the ED, Alexander informed the front desk that his gender identity did not match with what was recorded on his health card. This burden of needing to correct the information available in the DHIS after experiencing a traumatic incident compounded what he experienced. The sexual assault nurse attending to him did not consider his gender identity. Had the DHIS included "Gender Identity", careful attention could have been paid to this clinical encounter to proactively reduce re-traumatizing Alexander and avoid a dysphoria-inducing conversation.

Alexander verbally expressed his correct pronouns at several points during his time in the ED. In addition to consistent misgendering in the ED, Alexander reported that misgendering had occurred in his clinical records as well. In his hospital chart, it stated: "Female identifies as man; she presents with …." The use of incorrect pronouns within the chart itself is problematic, even if the patient never sees it. This systemic error perpetuates misgendering in later encounters as clinicians review previously documented care. "Pronouns" would provide a designated space for pronouns to be recorded correctly, modified for the patient when required, and promote a reduction in misgendering throughout all levels of the care experience.

Had the GHM been implemented and utilized as intended, the harms of being misgendered, deadnamed and outed would have been greatly reduced, and Alexander would have received the care he needed without having to endure these harms, which were levied despite his presentation in extremely sensitive circumstances (i.e. sexual assault).

4. Impact and Lessons Learned

The HL7 GHM was designed to enable affirming clinical interactions and care. The implementation of the GHM can reduce the risk of negative experiences like Alexander's in healthcare. It supports the duty of nurses to provide inclusive care for all people and a movement towards more inclusive educational experiences in nursing [14].

Nurse informaticists are optimally positioned to influence informatics practice and policy change for inclusive patient care within their organizations. Nurse informaticists may provide guidance in procurement processes by advocating for system requirements for modern GSSO terminology. They may lead assessment of the use and re-use of GSSO data within the organization. For example, do clinical decision support systems use embedded sex information in written communication with the patient or are gender, pronoun, or Name to Use fields used? Are preventive screening programs using anatomical information rather than administrative identification data? Nurse informaticists may be involved in policy analysis such as patient control of information sharing and associated workflows. Value option sets for these new data elements and new data artifacts, such as anatomical inventories, need to be co-designed by people with diverse gender identities, clinicians, health terminology standards experts, policymakers, researchers, and software designers [15]. Nurse informaticists can take a leadership role in this co-design.

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