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Strategies for Effectively Documenting Sexual Orientation and Gender Identity in Electronic Health Record

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Abstract. In this communication we identify strategies for effectively documenting Sexual Orientation and Gender Identity in Electronic Health Records. For this review a multidisciplinary group composed by three physicians, a nurse, an engineer and a lawyer analyzed the evidence in bibliography related to the topic and summarized the results. After analyzing the information, we summarized and classified them into three major topics: To request, to store and to display and access to the information. How to standardize those data and where data specifically will be populated in EHRs have not been answered yet. The target of all of these efforts should be: to be sensitive with the needs of the patient and to ensure high quality of care.

Keywords. Patient Identification Systems, Health Information Systems, Gender Identity, Transgender patient

1. Introduction

Transgender people experience their gender identity (GI) as different from the sex which was assigned to them at birth.(1) Gender transition may be thought of as the process through which one aligns one's physical sex with one's GI. Not all transgender people will seek a medical transition, it might be a social one.(2) Transgender people can be heterosexual, homosexual or bisexual in their sexual orientation (SO). Transgender patients have particular needs in what concerns to demographic information and electronic health records (EHRs). Specifically, they may have chosen a name and GI that differs from their current legally name and gender. Using the wrong pronoun or name in a transgender patient may provoke distress, ridiculousness or even violence performed by others in the waiting area. Transgender people face intense health disparities and lack of access to health care; failure to accurately document transgender identities increase these disparities through negative implications.(2–5) A study focused on young adults lesbian, gay, bisexual and trans-sexual (LGBT) population, looked at their self-reports of how much acceptance and support they received from their families as they came out

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and the current status of their health. For those who got little support, the adverse effects were worst including suicidal ideation or attempts, serious depression, drug abuse, etc.(6)

The first step to ensure high quality of care is identifying transgender patients. In order to achieve this, health information system (HIS) has to be adapted to register and maintain a history of the changes concerning patients´ GI. On the other hand, insurance companies require name and sex to be recorded in EHRs as they are listed in the Identity Card (IC). Transgender patients report that they feel empowered when their preferred name and pronoun are recorded in EHR, an increasing number want to self-identify as such, despite the fear and anxiety they may experiment about doing so.(6) They do want people to know how to communicate with them respectfully and accurately.(6) Other issues to consider are how to standardize SO and GI data and where exactly to place it in EHRs.

The Institute of Medicine(4) and the Joint Commission International (JCI)(7) have each recommended that data on GI and SO must be collected in EHRs. Office of the National Coordinator for Health Information Technology (ONC) believes including SO and GI in the 'demographics' criteria represents a crucial step forward improving care for LGBT communities.(8) The ONC announced that they will require that all EHR systems certified under the Meaningful Use incentive program have the capacity to collect SO and GI information.(9) The goal of all of this activity is to collect data that will be able to trigger alerts for screening and preventive health services, track quality metrics and create research opportunities. Most frequently HIS only watched the patient's birth-assigned sex. In Argentina, after GI law sanctioned in 2012, transgender people have the possibility to regularize their situation respecting their GI.(10) The law also contemplates cases in which people have not changed their government issued identity documents, so they are currently listed with a name and birth-assigned sex. According to the law, health care providers must respect if a transgender patient has preferred names and/or pronouns that differ from those listed on government-issued documents or health insurance policies.(10) Consequently, health care registration systems need to be modified in order to reflect patients´ anatomical sex and in turn, their chosen GI and new name. In this communication, we identify strategies for effectively documenting SO and GI in EHRs.

2. Methods

For this communication a multidisciplinary group assembled to discuss the topic was formed with the participation of three physicians, a nurse, an engineer and a lawyer. With the purpose of include relevant and diverse literature, we performed a comprehensive search through computerized databases: MEDLINE, LILACS and internet search base engines, using the following keywords: transgender, gender identity, LGBT, electronic health records, electronic medical record, transgender law. Only texts written in English and published over the last ten years were included. The reference lists of papers were hand searched to identify additional literature. Research articles were evaluated by the group with regard to quality, applicability and relevance, and finally the results were summarized.

3. Results

The strategies for effectively documenting SO and GI in EHRs, were summarized and classified them into three major topics: To request, to store and to display and access to the information. Several publications have described which data to collect and how to do it, but limited guidance exists for EHR development teams, like a practical guidance on what actual workflows would look like for end users.(3)

3.1. To request the information:

Asking patients about their SO and GI is a challenge. A technique named "two-steps questions", to allow the collection of GI information has been shown to be superior at identifying transgender patients in comparison to other methods.(2,11) This technique first asks about patient´s GI and then about birth-assigned sex. By asking about SO as a standard demographic variable, providers may facilitate patients to come out and share personal and more accurate information.(6,12) Also, it is crucial to mention that it is not a health problem that could be added into the EHR problem list. Patients should be assured that this information will be confidential and providers should ask for permission to include it in the EHRs, reminding patients of its importance for healthcare quality. Privacy and confidentiality concerns are exacerbated by the increasing computerization of health records.(13,14) It is also important to have educational material for patients to understand why it is important to carry a history of reports on their SO and GI changes. Effort also must be focused on patient´s self-registration process, where ideally a web portal system will allow patients to enter their own demographic information. This has shown to increase the likelihood of honest answers.(13) In any of these cases, it is important to always maintain an opt-out option available.(6)

3.2. To store the information:

"Gender ID data" can be defined as a group of data, including: GI, birth-assigned sex, legal sex, preferred name and legal name.(3) According to this, Deutsch et al.(3) proposed the implementation of three gender fields: GI, Birth Sex, Legal Sex. In addition, they recommended a Preferred Name field. They provided an exhaustive description of three possible patient scenarios and suggested solutions.(3) The three cases described are:

First case: A transgender patient who has not changed any legal documents to reflect his/her GI, so GI differs from birth-assigned sex and legal sex. Example: GI = male, birth-assigned sex = female, legal sex = female.

Second case: A transgender patient who has changed the legal documents to reflect his/her GI, with GI and legal sex that are the same and birth-assigned sex that is different. Example: GI = female, birth-assigned sex = male, legal sex = female.

Third case: A transgender patient with GI that differs from birth-assigned sex and legal sex (which are also different). Example: GI = genderqueer, birth-assigned sex = male, legal sex = female. This would represent a genderqueer-identified person, assigned male at birth, who, when faced with the requirement to choose from either "Male" or "Female" to be listed on legal documents, chose "Female".

EHRs have to provide resources to store an inventory of a patient's medical transition history and current anatomy. An anatomical inventory would allow providers to record into the chart and update as needed, the organs each patient has at any given

point in time. This inventory would then drive any individualized auto-population of history and physical exam templates, it also should be uncoupled from the patient's recorded GI or birth-assigned sex.(15) A list of commonly sought treatments and procedures, which may not be listed in current systems should be included as selectable items in the medical history.(2) The terms should be incorporated into controlled vocabularies. These procedures, however, also should be uncoupled from any gender-coded template.

3.3. To display and access to the information:

The system should notify providers and clinic staff of a patient's preferred name.(2) On the EHRs, patient's header preferred name and pronouns should be displayed prominently so anyone can see them immediately upon consulting the chart. Banner "name" field could be driven by legal name for all patients except for those who have an entry in the preferred field, the presence of which serves as a Boolean flag to drive the routing of the preferred name to the banner in the place of the legal name.(3) Asterisk (*) or other alert icon could be displayed in the banner for any patient whose GI differs from legal sex, and/ or any patient whose preferred name is different to legal name. This notifies staff that they must utilize other demographic information not displayed on the banner in order to verify identity, process billing claims, etc.(3) Electronic processes such as billing, printing prescriptions and lab labeling can be driven on the back end by legal sex and legal name fields. Patient education materials can explain the need to retain and use legal identifiers in these settings.(3) HIS also should allow sharing patient's marital status or identifying a partner, for advance directives and health information.(15)

4. Discussion

In actual fact and because the majority of patients are not transgender, a binary male/female oriented system across multiple platforms such as EHR exists; however, this structure inhibits the collection of accurate medical information, so it should be modified.(2) Patients may feel that being confronted with routine SO and GI questions is disempowering.(6) If routine SO questioning is incentivized or otherwise encouraged, it will be essential to provide widespread patient education and empowerment activities.(6) In addition to the development of ongoing patient satisfaction measures to ensure patient needs of improved care.(6,15) The primary concerns about collecting data on SO and GI are related to privacy and use: who is going to ask these questions, what training will they receive, in what context will they ask them and to what extent will the information be available within the healthcare system. Patients need to understand why the issue is important and what they are being asked to do. Inexperienced staff in transgender care may find these non-binary GI and terminologies to be particularly difficult to understand. Inclusion of an added real-time reminder or pop-up for patients whose pronoun preference is "They/Them" within the user interface may help reinforce this behavior among clinic staff and providers.(3) It has to be possible to provide a high level of monitoring on EHRs for inappropriate access and use. It might be set to follow all those who declare SO and GI minority status to ensure there is not improper use of their data. Unauthorized access or sharing of information should be punished. Other issues to consider are how to standardize SO and GI data and where exactly to place it in the EHR. Hopefully, the technical community will come to an agreement soon on how

to collect SO and GI data, how to standardize and where specific data will be populated in EHRs.(6) While a standard that all vendors could follow would be ideal, what will likely happen is that each vendor will develop their own standards and then work together to map fields from each other's EHRs so that they can exchange data accurately.(6) As institutions begin to demand appropriate and insightful EHR functionalities, vendors will respond to these demands.(3)

5. Conclusion

To document "Gender ID data" into EHR is a challenge to health providers as well as vendors. In this article we summarized existing recommendations. How to standardize those data and where specifically should be populated in EHRs are still unanswered. The target of all these efforts should be patient needs and to ensure high quality of care for them.

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