Humanistic Charting: Standardizing a Patient's Person and Voice into the Electronic Medical Record

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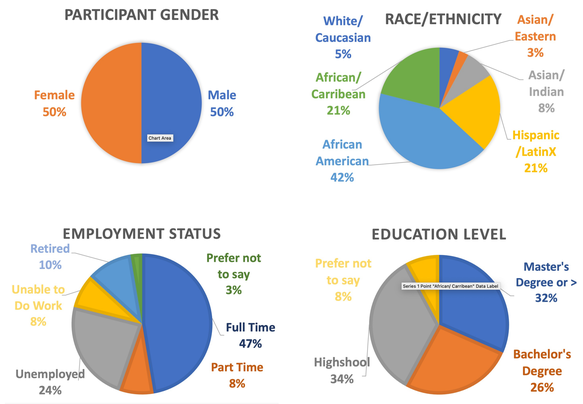
Background

- The verb **standardize**, is defined by the Merriam-Webster dictionary as "to bring into conformity with a standard, especially in order to assure consistency and regularity."
- Standardization of health care processes, particularly the utilization of information technology (IT) like the electronic medical record (EMR), have been credited for improving patient safety and quality of care (1).
- It is important however to also assess potential balancing measures (unintended consequences).
- As noted by Paul Batalden "**Every system is perfectly designed to get the results it gets**,." leading us to ask: What is the **standard** to which we are **standardizing**?
- In a TEDMED talk, Mitchell H. Katz (2018), now President and CEO of the New York City Health and Hospital (NYC H+H) System, described how our countries health care system is structured towards a **middle-class model** (2).
- This **'standard'** assumes adequate social resources (housing, food, utilities, transportation etc.), insurance, literacy, and the privilege of being able to prioritize one's health.
- Since in reality there is no homogenous patient population, the implicit assumption of a consistent standard and/or solution likely does not exist either.
- The critical question what happens when patients don't meet that '**standard**' and how it impacts their health and the care they receive?
- The premise and beauty of the United States is rooted in its **heterogeneity;** respecting the individuality of each patient is critical to providing effective and just health care.

Objectives

- To develop a tool, grounded in the patient 's own voice, to allow a more humanistic snapshot of who the patient is (aka Humanistic Charting); that is easy to use, and effective in documenting their '**person**' in the EMR.
  - **'Person'** is a term commonly used in this study. The qualitative portion of the study, working with our patients, is designed to identify how this term is to be defined and documented.
- To assess the impact of the tool on 1. patient care experience and 2. medical decision making.

Demographics



Methods

- This is a mixed methods descriptive study conducted in 3 phases. IRB approved.
- Phase 1: Qualitative data collection (completed)
  - N = 38; Key informant interviews (8-74 minutes); audio taped and transcribed verbatim
  - Triangulation: Participants included employees and patients from:
    - 2 Post Acute Care/Skilled Nursing Facilities: Gouverneur and McKinney
    - 4 Acute Care Hospitals: Harlem, Bellevue, Jacobi, and Lincoln
- Phase 2: Tool creation (in progress)
  - Workgroups: Study team will work with Patient and Family Advisory Councils (PFACs) from 6 different acute care hospitals: Bellevue, Jacobi, Lincoln, Kings County, Coney Island, and Metropolitan.
  - Feedback focus groups with PFACs using interactive prioritizing of what questions for each core area should be used in the patient tool

  Phase 3: Quantitative/Qualitative – Pilot (May/June)
  - Validating the effectiveness and useability of the resulting tool to create a more humanistic version of the patient' persona:
    - Outpatient/Inpatient pilot: at Bellevue and Jacobi Hospitals. Assessment will focus on care experience and provider satisfaction metrics.
    - Case scenarios of patients presenting with various conditions will be sent to two groups of providers; one group will also receive a brief patient profile (Humanistic Charting); providers will then be asked for their diagnosis and treatment plan. Assessment will compare the two groups to determine if having Humanistic Patient Charting information impacts clinical decision making.

Results: Defining 'Person' and Showing its Importance in the Context of the Medical Setting

4 Core Areas were Identified

Self Narrative: enabling patients to describe themselves

Health Goals: consistently empowering patients to inform providers of their goals and needs (immediate/long-term)

Care Preferences: ensuring providers know preferences in relation to care, communication, improvement, etc.

Variation: alongside questions related to social determinants of health, other important circumstances that could impact care provided. Documented and consistently updated by patient.

40 y/o M living with Bipolar Disorder with psychosis: "I am a self-loving individual who believes that most people on this planet are heavenly in their hearts, and therefore deserve to go to heaven. I am not a very religious person, but I do believe in heaven. After college I worked in the military and then got my degree as a civil engineer. My favorite things to do are playing a piano, I play jazz piano, and have been playing since I was 6 years old. I really enjoy writing music, songs, lyrics, etc. The most important thing to me is something called self-love, important and a foundation for anyone's life."
How do you think your health care provider describes you? "I think they would probably say I have bipolar disorder. I think they see me as myself at first, but after a while, I think it is kind of after dealing with the patient, you know, who's got illnesses and stuff, I think that their opinion of me, as a person, falls off, it always falls off."

72 y/o F living with MS, Mandarin-speaking: "I see myself as a good and compassionate person. I have spent more than 10 years here, and I have work in Hong Kong and I also work here. I have good relationships with other people. I have my Christian faith and I don't get into argument with other people. Usually I even in more difficult situations I would just put up with them and I feel like I am a very friendly and accommodating person."

Patient Above: "If I have an illness, I would like to talk, I would like the doctor to be able to explain the illness to me in more in a more detail way and I hope that our interaction is it's warmer and that I won't feel so intimidated. When I talk to the doctor, I want the doctor to be more approachable and our interaction to be more interactive/nice."

49 y/o F hospitalized for pancreatitis: "I will say that I am. I'm a whole lot of things, a liar I'm not. But I'm I'm a very caring person. I wear my heart on my sleeve. I care about a lot of people's feelings I care about I always think about other people. I put other people first before I put myself first and that's yeah, pretty much."

Patient Above: "That I have to stay alive long enough for my children. It's funny because you can never be prepared for death. . So I got at least a good 25 years if God permits me, but for me is, at least so my kids are like in their early 20s. Please take care of me. Please take care of me. Think of my children. My loved ones."

48 y/o M hospitalized for heart failure: "I am different, different from what I was as a teen, as a 20 something, I am not just what you see now. I have a son, my wife, and a good sized family. My favorite thing to do is hanging out with my nephew and my son. We play videogames and really enjoy hanging out."
How do you think your health care provider describes you? "Morbidly obese…Yeah." (frustrated/sad demeanor)

Patient above: "What's important, being able to get back on my feet, I hate, I hate needing, I won't say hate, hate is strong. I really dislike needing help. my greatest wish, or what I really don't want to do is get back to my family on my feet. I want to walk home to them."

Patient Above (to the Right): "It is really difficult in my neighborhood, as far the food, the supermarkets, the food together on the street, the burgers are cheaper $1.99 and the salad is $10. Don't get me started on the housing."
Is there anything stopping you from accessing healthcare? Any barriers? "You know, there's plenty of insurances. My mom, she has insurance, but doesn't qualify for Medicare yet. I'm on Medicaid, but you know like my mom, she has to pay a certain co-payment or pay for her medicine, because she wasn't on public assistance. She worked all her life. And so she would say she has a pension, so on and so forth. You know often they're not able to get, you know, their medicine, they have to pay for their medicines themselves."

Discussion

- Of the 38 participants, 29 felt that their health care provider does not know their 'person', 7 were unsure, and only 2 felt known.
- Patients are not their illness/condition. They are not at their best when their providers meet them and feel that they are unable to clarify this, including how the complexity of their lives creates barriers to the success of their treatment/care.
- Most believe that the providers see them in a light that negatively impacts their care and that they are powerless to correct this impression. They hope for more connection and being seen as their true 'person' by their providers.
- As New York Cities' municipal health care system, NYC Health + Hospitals takes care of all New Yorkers, regardless of their background and ability to pay.
- In order to provide effective services to NYC's diverse patient population with its many complex challenges, thorough and effective documentation of this information, that is easily accessible is needed.
- This tool created by patients, used by patients, and under the control of patients **and** providers, enables already overwhelmed health care practitioners' access to this critical data, enabling more effective treatment/care.
- Here at NYC Health + Hospitals, we see the importance of and are committed to treating the person alongside the patient and the disease.

2022 Gold Humanism Virtual Conference - Humanistic Charting Patient Profiles: use this QR code to read a few patient profiles.

Citations

1. Kern LM, Barrón Y, Dhopeshwarkar RV, Edwards A, Kaushal R, HITEC Investigators Electronic health records and ambulatory quality of care. J Gen Intern Med. 2013;28(4):496–503. Epub 2012 Oct 3. [PMC free article] [PubMed] [Google Scholar]
2. Katz, Mitch. (Oct 24, 2019). *What the US health care system assumes about you | Mitchell Katz* [Video]. YouTube. https://www.youtube.com/watch?v=n3ZbjsS4TCc&t=12s