

Narrative Health: Using Story to Explore Definitions of Health and Address Bias in Health Care

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ABSTRACT

When defining health and illness, we often look to governing bodies such as the Centers for Disease Control and Prevention and the World Health Organization rather than our communities. With health disparities prominent throughout the US, it is important to look at the structures we have set forth in health care and find new ways to address health as well as new definitions. Storytelling is a valuable tool to help understand how our communities address health and the place of the hospital or clinic in their health. Narrative Health focuses not just on storytelling but also story listening. At the Community-University Health Care Center in Minneapolis, MN, we have implemented narrative health programs with patients and learners from various health professions. Using creative writing pedagogy and techniques to decentralize the practitioner-patient binary of illness, we learn about our patients' stories of health and experiences with health care. It is important to move past the definitions of health to the complexities of story that allow for the human aspects of illness to be absorbed and understood.

INTRODUCTION

When speaking about health, we need to broaden our parameters and define health in a way that includes the social determinants of health, that is, those elements of health that are structuralized and take into account geographic regions of people, their work, age, education level, race/ethnicity, sex, gender, and numerous other elements of a person's life. The role of a health care center, such as a clinic or hospital, is limited in a community. Health care centers must find ways to build relationships in the surrounding communities to better understand the needs of those communities and how the health care centers can best meet those needs.

America has one of the largest income-related health disparities in the world regarding patients' past experiences and future access to care,¹ and in Minnesota there are persistent health inequities along lines of race, economic status, sexual identity, disability, and geographical location.² To begin to address these inequities, we must look at the structures that created them and listen to our communities and the stories they tell about how they define health and the clinic's place in their health. Storytelling is a useful tool that crosses ethnic delineations and is a powerful way to begin understanding how to address inequities and bias in health care.

Storytelling is well used in medicine and other professions to help connect practitioners to their clinical practice on a more emotional and empathetic level. Sometimes situated in medical humanities or called narrative medicine, a term coined by Rita Charon³ in the early 2000s, storytelling in medicine is presented

as a means to bring back the communication stream often lost between physician and patient. Rita Charon defines *narrative medicine* as "medicine practiced with narrative skills or recognizing, absorbing, interpreting, and being moved by stories of illness."³ Although narrative competence and skills are important, we need to move past the idea that health is completely encompassed by the realm of medical practice. By focusing on people in communities, we can begin to understand social determinants of health and paths to health equity. We must listen to the stories of those in the community, their definitions of health, and the issues they see as important to the health of individuals, and the health of their community. Thus, we need to move past narrative medicine and toward narrative health.

HISTORY OF DEFINING HEALTH

The World Health Organization defines *health* as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."⁴ This definition is the first principle in the preamble to the World Health Organization's constitution, which was ratified in 1948.⁴ *Health disparities*, according to the Centers for Disease Control and Prevention, are "preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups, and communities."⁵ However, these definitions of health and disparities were likely not created in the communities to which they are applied. The community where we work, the Phillips neighborhood of Minneapolis, MN, is an economically and ethnically varied area with many new refugees and immigrants. The Community-University Health Care Center (CUHCC) is bordered by both the Indian Health Board and the Native American Community Center. CUHCC has one of the most ethnically diverse patient bases in the area, with a high number of patients who are Somali or of other African descent, African American, Hispanic/Latino, and Asian American (Hmong, Vietnamese, and others). Only 17% of our patients are of European descent as of the 2016 Uniform Data Systems data. If we reached out to our communities to define health, would it match that of the World Health Organization? When speaking of health disparity, would our tight-knit communities feel socially disadvantaged?

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These questions are especially important when we discuss health equity and equity in general. When we speak in definitions and those definitions are created by a dominant group, we are speaking in a very denotative, or literal, manner. This flattens and removes the complexities involved within an issue. The idea of the sound bite definition, or oversimplification to garner interest, as it is used in marketing and the media, has led to a loss of understanding and pushing beyond the one-liner to better define, and thus address, a problem.⁶ In simplifying these problems for a mass audience, the media also leave out entire groups of people who may be in more dire need of intervention or prevention. This shifts focus to the negatives of a problem and does not explore the ways people can prevent, identify, or deal with the issue together.⁷ For example, although much has been researched and discussed in journal articles about the current opioid crisis, information in the popular media such as news broadcasts and newsstand magazines focuses on the numbers of people who are overdosing, but not as often on prescription practices or underlying issues, including mental health and loneliness, that lead to substance abuse. By simplifying the language used, we lose the meaning behind words. Words have both a denotative and connotative meaning. Through storytelling, one reunites words with their connotative meaning, focusing on the language and emotions to create stronger understanding. When speaking of health equity and disparities, we need to speak with history and emotive awareness. To do that, we move to story.

Storytelling is unique in bringing contextual relations between various areas important to the storyteller.⁸ It allows the storyteller to connect their physical health to their mental, social, religious, and other realms of health providing a holistic approach. This provides a wealth of data about perceptions of equality, either directly through the story or indirectly through the ways in which they physically tell the story such as tone of voice and body movement.⁹ For many of CUHCC's patients who come from countries with oral traditions, such as Somalia, storytelling—and more importantly story listening—is a way to access definitions of health in our community along with how the community views realms of health and how to partner with health care centers. Story is also an important tool in historically underserved populations, which are often not heard in modern medicine or have their form of healing viewed as alternative or complementary medicine. In addition, the ever-increasing number of foreign medical graduates practicing in the US bring their own culture and language into practice and communication with patients. Storytelling networks are important to increase civic engagement, enhance a sense of belonging, and reach audiences left out of modern mass media.⁷ This is why the move toward narrative health is important. Narrative health asks us to thoughtfully examine who is telling a story and how they are telling the story (with a focus on how and who is defining health), to listen intentionally, and to share stories both between and within communities.

THE MOVE TOWARD NARRATIVE HEALTH: E PALLAI'S STORY

My family—mother, brother, and cat—and I were homeless for part of my childhood. We lived in a tent, going from state to state, before settling in New York, where we lived in a garage.

Even before then, before our items were sold and we packed everything into a car to spend time on the road, a modern-day Joad family looking for work, we were struggling. I remember our main meals coming from the school lunch program. I remember going to the grocery store garbage bin at night to supplement what food stamps provided.

There are many reasons that lead people and children into homelessness. Even though I lived through being homeless as a child, I will never fully understand all the complexities that led us there. What I do remember thinking would help us was, "If I only had a voice."

In school we take English class to strengthen our voice so other people can hear us. I was put in speech therapy to remove my accent (or lisp depending on who is telling the story), and to further strengthen my voice. That phrase, "strengthen your voice," was heard a lot, and I still hear it today. It's what led me to become an English teacher—to help others strengthen their voices as I had, so they could get a good job and be heard. I wanted to help others by teaching them to speak and write properly. Thankfully, I learned this approach is wrong when looking at the core of what I wanted to do—help people be heard and ease their suffering.

In learning to strengthen my voice, my history was erased from my speech. As I continued to grow, going to high school and then getting a scholarship in another city, I became alienated from friends and family who thought I was abandoning them. I had to code-switch among groups of friends, and there were those who felt I no longer could understand them because of how I spoke. In telling those who were as disadvantaged as I was in childhood that to be heard they needed to speak like others, as I was now doing, like those outside their communities, I was helping to alienate. When we tell people to strengthen their voices, we are telling them we are not ready to listen to them where they are. Indeed, that we won't listen until they speak in a manner closer to ours. It is the difference between asking someone to assimilate and become like us rather than integration, which requires compromise on both sides. We are adding another layer of burden on those who are so terribly burdened to begin with.

This is not to say that English as a Second Language classes and other initiatives are not helpful, but that when approaching our communities, our number one focus should be to listen intentionally and purposefully without judgment of language and traditions in their storytelling. This is what led me to move past narrative medicine and to look for a new paradigm, a new word to encompass how important it is to listen to who is defining health in a community and to mutually share stories, not have medicine and communities stand on opposite sides of the room. To understand something as complex as health, we can not only listen or not only speak. We need a circle where we share and listen freely and synthesize our ideas of health with others as equals.

PRACTICING NARRATIVE HEALTH

We must fully acknowledge the sound-bite nature of any word that talks about storytelling. The need to market to professionals requires a phrase that can be used in pitch sessions to practitioners, directors, deans, and others involved in health care. The

term *narrative health* was developed to encompass the aspects of an interprofessional community outside just medicine, one that includes the community and patient as a vital part of our learning and stories. At CUHCC we conduct 2 Narrative Health workshops: 1 with learners only and 1 with patients and learners together. When speaking with patients, we discussed the idea of narrative health in earlier sessions but now have changed to call it storytelling or just narrative workshops. We also focus on calling our patients “community members” during these workshops, to mitigate the practitioner-patient power structure. For ease of this article, we will continue to use the term *patients*.

Learner-Only Workshops

As part of the University of Minnesota, CUHCC is home to a number of “learners” (students in the health professions) for their continuity clinics, internships, or clinical rotations. Learner-only sessions offer a place for an interprofessional group of students and residents to discuss health issues together while exploring the intersections of their growing professional identities. In these sessions learners read a selected piece of writing ahead of time to discuss with the group before working on a guided writing assignment. Readings vary, from selections from graphic novels and memoirs, to short stories, case studies, and poems. Care is given to include readings from authors of diverse backgrounds. Selections from anthologies such as *Beauty is a Verb: The New Poetry of Disability*,¹⁰ *Women Write Their Bodies: Stories of Illness and Healing*,¹¹ *Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers*,¹² and *The Remedy: Queer and Trans Voices on Health and Health Care*,¹³ along with writings by authors such as Sherman Alexie and Lynda Barry, are explored through a creative writing lens. We first discuss the readings as elements of literature and what drew us in as readers, before we talk about the implications to health care and development as a practitioner. For example, when reading Sherman Alexie’s¹⁴ short story, “What You Pawn I will Redeem,” we opened with general thoughts about the writing style, the winding narrative, and initial reactions. We talked about the frustrations of narrative styles that occur in differing populations, and then we discussed experiences during patient encounters that mirror the protagonist’s narration. This led to us debating how information was relayed in the story, and in real-life encounters, vs what learners are taught in their respective schools. From there, the discussion moved to social determinants of health—those presented in the story and those that might lead a patient to “noncompliance.”

We approach the writing section from a creative writing model that involves 2 to 4 prewriting questions before beginning the final product. This helps the learners get past the initial response to their reflection and learn more about themselves, language, and how others use language. They may be asked to try a different narrative style, or write a poem, or write from their patient’s point of view. They are also asked to explore times when they were ill, to connect themselves with not just their patients but also times when they themselves were a patient. By using creative writing modalities, we can gain the benefits of reflection, bringing in empathetic models and recognizing we

are all part of the culture of illness. We also gain the benefits of creative writing, which include language usage, differences in tone and mood, and other aspects important to story.¹⁵

Learner and Patient Workshops

In these sessions CUHCC patients and learners are paired for a story writing exercise. Learners are instructed beforehand that they are to listen to the patient and to help as the patient instructs. In some cases this means being a scribe and asking probing questions focused on the patient’s story. That is, to focus on the sensory events being told rather than the medical ones, such as how it felt to lie on the gurney in terms of physical sensations (cold metal, straps too tight, or itchy) and emotions. Learners are not to diagnose, but simply to listen. If the patient does not want to work with a learner, the learner writes his/her own story alongside the patient.

We begin with a reading that is short and read it aloud. These can be published materials, or one written by a group member in a prior session. Much like the learner sessions, we discuss the reading as a group before going into our prewriting, leading to the final product. At the end, everyone is encouraged to share their stories. We discuss what we liked and want to know more about vs comparison or diagnosis of illness. We also discuss the way language is used. Learners are encouraged to share alongside the patients.

We do not limit the writing to English. One of our more impactful sessions included a Somali man who brought a poem he wanted to share about battling his addiction. He read it in Somali, and those who understood the language were moved to tears. We had a group member who served as a Somali interpreter say it was too beautiful and complex a poem to translate into English. The emotions were raw and visible in people’s reactions, leading us to comment on how moving it was despite not speaking the language. A debrief with learners later led to a discussion about how this mirrors what happens in the clinic on a daily basis. Often patients who do not speak English come into the examination room, and we need to understand each other, with or without an interpreter. It also gave us a chance to reinforce that a community does not have to speak the same language. We are a community connected by health and illness, linking us in a common humanity.

Benefits of Narrative Health Workshops

Narrative Health workshops were initially conceived as an educational intervention to teach future health care practitioners varying ways of communicating with a focus on listening. It was also meant to broaden their understanding of how health is discussed and defined by providing a number of voices, often underrepresented in their education. One of the themes we are seeing in our patients’ writing is how they feel healthy when connected to other people and their community, such as in Ishmael Amin’s story in which he is happy eating Somali food with a friend, or in Michael Southard’s story in which we learn how being placed in an Indian Boarding School for Native Americans as a child still affects him today (see Supplement: Patient and Learner Stories). This expands the medical view of health from residing inside the body to the wider community.

Comments from learners include the following: *[The Narrative Health workshop] helps me to slow down and listen to my patients' stories to help me cooperate with my patient to create a better therapeutic plan; [it] made me think differently about how patients perceive what I consider good care. I remember hearing a story about a procedure that I thought was so great [but] that the patient found disorienting and terrible, and I think it helped decrease the differing power dynamics between patient and provider.*

An added benefit is that it also promotes learner wellness by having a dedicated space for reflection and to discuss developing identities outside the technical, or denotative, realms of their professions. We have found this reconnects students in the human aspects of health care. So often in health professions the scientific aspects are addressed, but the personal and humanitarian aspects, when discussed at all, are given less weight. These sessions, particularly the patient/learner ones, have helped facilitate learning from lived experience in addition to books or simulated experiences.

Patients in the workshops have discussed feeling empowered to speak about their health without worry of diagnosis or practitioner agenda. Some have said that within the group setting, it feels like therapy to have a space to be heard. Others find that the act of writing the story, even if not shared, still helps. On the clinical side, practitioners whose patients have attended said they learned things in their patients' writings they had not learned after 2 years of working with them. Although we do not share patients' writing with their practitioners, the patient sometimes brings it to an appointment to share. Patients have even brought in writing to share with the group that they had continued to refine at home after a prior workshop. Through this, we are creating a community, learning to listen to all of our definitions of health, and strengthening that first step toward health equity—acknowledging that the voices and experiences of others are important and must be heard so we can find solutions together.

CONCLUSION

Narrative Health workshops at CUHCC have helped us and our learners open lines of communication with our communities and better understand their social determinants of health. Through patient and learner sessions we are learning more about the variety of voices in our community. We are also providing an open forum for listening, an often forgotten or not explicitly discussed part of communication, and empowering patients. By holding these sessions in authentic language and voices, learners can access the emotional aspects of language and health care. This has allowed us to teach the next generation of health practitioners the importance of narrative health and of listening to their community, one they are a part of, and how health is truly defined by our patients and even ourselves, as we are not outside the humanity of health and illness.

We have much room for growth in our program. We would like to expand to involve other community centers and more members of the community. By bringing narrative health to the community and outside the clinic, we can also gain a better idea of where our place is in the greater community. We would also

like to see more staff involvement so the lessons learned are not just for our health care students, but for everyone in CUHCC. Another aspect we would like to explore is collecting these stories for a wider audience to see how the voices of our community define health. We want to have their stories stand alongside the more dominant voices in health care—those of the physicians, other practitioners, and bigger organizations that define not just health and health care but also access to those services and what is necessary. In those ways, we hope to expand narrative health to better understand and address health disparities in Minnesota and beyond. ❖

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Supplement: Patient and Learner Stories

When writing in Narrative Health workshops at Community–University Health Care Center (CUHCC) in Minneapolis, MN, patients are guided through writing prompts asking them to write about a “moment” on their health journey. Narrative styles differ greatly among our patients and cultural backgrounds. We honor their stories as they have shared them with us and provided a cross section of our population.

A MOMENT ON THE HEALTH JOURNEY

Below, a patient writes about getting a diagnosis and beginning to address her illness after 11 years of living with it.

Untitled

By Christine Hoey, CUHCC Patient

Nervously waiting, listing all my symptoms. Answering questions very few have previously asked. Feeling heard by the right Drs and told what I had finally. Hearing steps to be taken next. Dr observing every movement and noting what movements were. Checking thoroughly and a diagnosis finally! I know what I have and can finally address what can help and learn to live with what can't be controlled. And today it snowed! 1st in 34 years for me and it made it a beautiful day.

Fear and anxiety alleviated and better health is the goal. ❖

SENSORY ASPECTS OF ILLNESS

In this prompt, participants were asked to focus on the sensory aspects of an illness they had. Here, a pharmacy resident writes about nasal surgery

Scents of Home

By Ajay Patel, Pharmacy Resident, 2017

The pressure of metal tweezers,
Reaching far in.
Plastic sliding down my skin.
Fluid, gushing out with no end.

Clang of metal on metal
Tweezers fall to the tray,
Holding a plastic splint,
Covered in thick obstructive mucus,
Streaked with black, lined with blood.

The deep grumble of his voice,
“How does that feel?”

Air rushes in.
My lungs feel full for the first time.
High on oxygen.
Giddiness.

I return home,
Elated by the return of a long-lost sense
Overwhelmed at what I've been missing.
A room full of smoke from burning incense,
Comforting and familiar.
A tingling burn gives new happiness to an old comfort. ❖

A “MAGIC LANTERN”: EMOTIONAL SUPPORT

In this session, learners were to write about a “magic lantern” something they have imbued with special powers and look to for emotional support. Here, a pharmacy resident writes about her hairclip

Little Black Clip

By Dema Mohammed, Pharmacy Resident 2018

A black hair clip that looks like any other, a little bigger than most but smaller than the biggest. It has a few gems on it, a couple missing. It takes me back to the time it went missing. I was so hung up on trying to find it. You see, this hair clip was unlike any other. It's the only hair clip that has lasted its time, it's the only one that can hold up my hair in one try. I need it with me for without it I feel lost. Some days when I don't feel strong, I rely on my hair clip for seeing how small it is but thinking about what it can do gives me hope. After I had lost it and found it I would never lose it again. It needs to be in sight, clipped onto something I would have with me for those times in need where I've had enough when I want to just throw my hair up and feel comfort. All of this from a hair clip, one unlike any other, my hair clip. ❖

MEMORIES OF MENTAL ILLNESS

Here one of our patients, prompted to write about a moment on her health journey with a focus on the sensory experiences of the moment, writes about the day she was committed to a psychiatric unit.

Untitled

By Uma Oswald, CUHCC Patient

It was a sad little square room. The door was thick and heavy as it clanked shut behind me. It was locked—I heard the door lock. Feeling slightly frightened, like a caged bird, I walked over to the makeshift hospital bed—it was on wheels—and curled up in the fetal position, hiding under the blanket like a child. The lights were dim—I wanted them off, so the blackness would consume me and I could pretend I was somewhere else. The harsh light, the only bright spot in the room, came from the sliver of a window on the door that was connected to the doctor's office. I knocked and the doctor, a petite woman opened the door. Of little I could see of the office, it was a whole other world. “I'm feeling okay. You know I really don't think I need to be here.” She knew I was lying. She said I had to stay. So much for a quick escape.

I went back to the bed, and somehow, sleep overtook me. I did not know what time it was when they came for me. It was the damn doctor and a male and female EMT. They strapped me to a gurney. I tried not to shake. I was trying to be brave. I smiled and conversed with the Euro EMTs. I laughed.

I did not know where I was going, but I knew it was a psych ward, where mentally disturbed people went. I pictured a county jail cafeteria-like room, surrounded by a cage, doctors on the other side, staring at us like we were monkeys. ❖

A FAMILY MEMBER'S PERSPECTIVE

In this poem, a pharmacy resident writes about navigating the hospital for a family member's health, her role in her family, and the ways pharmacy is utilized—biding in pharmacy education to avoid tough emotions as well as being called on to handle the health care side of family illness because of her role as a pharmacy student.

Waiting

By Morgan Stoa, Pharmacy Resident 2018

The waiting room so warm and cozy
Comfy chairs, a wonderful decorated Christmas tree
People waiting, last names being called
When will I hear my own?

Focus on your work.
Finals are this week.
It will keep the worry away.

Good!
You made it
Where'd you park?
You will have to pull around here soon

My name!
How is she?
How did it go?
When can I see her again?
Pull the car around now, please
He just said so. I will walk back and get her

Cold, stale, sterile
White linen sheets, small frame shaking from the cold
She's always cold
Or is it the meds?

She needs socks.
Well at least put the left one on now.
I will drive home, just go pick up her medications.

"Why can't you just go. You're the pharmacy student.
I don't even know what I am looking for."

Discharge papers, IV pulled, rolled into the winter snow
Still shaking
Still cold
Got to get her home

Her last treatment was Monday.
I was never able to go.
The work and studying I used as a bandaid is now my entire life.
Not just a simple tool to distract myself but my whole and complete occupation.
What I wouldn't give to go to that pharmacy.

I hope it's at least warm.
Please tell me it's warm
As warm as it can be
Alone in a sterile white stale room. ❖

POSITIVE ASPECTS OF ILLNESS

In this prompt, we were focusing on positive aspects of our health journey. Here, a Somali patient writes about coming home from the hospital.

Untitled

**By Ismael Amin, CUHCC Patient
Practitioner-Patient-Interpreter Relationship**

I woke up and she was holding my hand.
Her eyes filled with tears.
I wondered, why she cried, the pictures showed me.

I came home and see my bed again.
I like the sky, it was deep blue on my discharge day, it reminds me of the power of God.
Shaking hands with friends again was a great feeling.
I ate with my friend Somalian food, rice with goat meat. ❖

Mohamed is a Somali-speaking patient at CUHCC. Here he describes what an appointment is like for him working with both a practitioner and interpreter. This was written with the aid of a fellow participant who spoke Somali.

Untitled

By Mohamed Yusuf, CUHCC patient

When I need treatment for diabetes, I go to the clinic here. After waiting in the waiting room, finally having your name called, and getting your vitals taken, you are left in the doctor's room. You wait, alone. You feel lonely. When the doctor comes, they tell you your blood work—if your sugar is high or low. If it is high, you feel unhappy. You are surprised when they have to increase the medicine. The doctor sits typing at the computer, but they look you in the eye when they talk to you. The interpreter translates word by word, so you can talk in your own language, Somali. When the doctor talks they listen—then they talk to you—and you listen. Then you tell the interpreter what you want to say—and they tell the doctor. That way, they answer every question you have. Then they will tell you what to do. You all sit there, in the small little room, in three chairs. If you have back pain, there's a place to lie down, and the doctor will examine you—here, pain? Here pain? Then she will decide what you need. They ask lots of questions, but it's okay. You feel cared for. ❖

REFLECTIONS ON CHANGE

Michael has been to almost every patient/learner writing session we have had. In his writing, he talks about the holidays, family, and being taken away to be put in a boarding school for Native Americans as a young child.

Untitled

By Michael Southard – CUHCC Patient

When my mom and dad split up, I had to go live with my grandpa. A lot of things happen while living with him. Though the one that hurt most was having to stay in a Catholic boarding school because my grandpa did not want to raise me. He wanted his freedom. So for grade school to Jr high school, I was there. While there I got into a lot of fights because I am a half breed. And the way the boarding school try to change me (into the white man's way of life). Not too long hair, not to speak our language, not to believing our higher power, and so on. And when holidays come I would be one of the two kids still there. Never being with my family, or relative. This is why I don't like holidays so much. Then not knowing my own language, to speak it, then all the fights with others, even my own cousins, and so on. This is why I don't like talking about my past because I go through so many feeling. Tough!! I got to do this in order to feel better, and work this out in a better way so I don't feel so scared. Though I will always not liking talking about it. There is a lot more. The one I talked about is just the tip of my past ... though I am working it out. ❖