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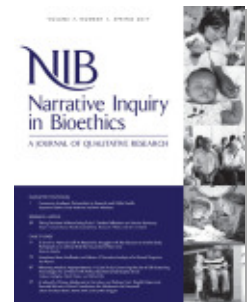
A Storied Community: Piloting a Patient/Student Narrative
Workshop at a Community Health Center

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When Amy called that adrenaline and fear kicked in and led me to tell her everything was fine. It was decidedly not fine. But you learn early on in transitioning to try to grow the thickest shell possible. That colleagues and acquaintances will say unbelievable things to you regarding your body and mind and most importantly question your ability to make decisions about yourself. You simply forget how to trust anyone even the people you see as friends and allies.

Later that week I sat in my provider’s office and discussed my case. I wondered afterward how my own healthcare advocacy would influence potential collaborations I had proposed with that department and that provider. I want OHSU to track and measure care for their TGNC patients as part of the THP. The publications around TGNC healthcare are largely found in Europe where the gender clinics and socialized medicine creates opportunities to assess care. The fragmented nature of healthcare in the United States means that most peer-reviewed research is community driven and published by clinics serving LGBTQ populations.

Conclusions

The event last year highlights some of the ethical issues faced by the both of us. Amy has established intentional practices on how to be more predictive about the potential for dual relationships between her personal and professional identities. Communication around her role in different scenarios is key, as the patients accessing care will continue to have personal and professional overlaps with THP staff.

Lewis is continuing to explore how best to navigate the thorny landscape of overlapping identities as well. He has been actively talking with a small group of TGNC healthcare professionals that also navigate this landscape. Trust was previously mentioned in this essay and that concept is key not only to the personal use of healthcare but also to the creation of research that evaluates that care. Fostering that trust as a professional while calling for healthcare accountability measures is a tightrope that Lewis and other TGNC healthcare researchers

walk with trepidation, always fearful of breaking the trust of the systems they are studying and/or the trust of the communities they are a part of that so desperately need this research.



A Storied Community: Piloting a Patient/Student Narrative Workshop at a Community Health Center

EmmaLee Pallai

The students enter the room unsure. They come from various health professions across the University: Pharmacy residents, Doctorate of Nursing Practice students, and medical students. For perhaps the first time they will be sitting with patients in a room that is not an exam room. They will be writing stories, not medical notes. Together, students and patients will be talking and writing about illness as people who have experienced it in their lives, not with their role in institutionalized medicine on their sleeves. The students have been instructed that, if asked, they may be called on to help the patients with the physical act of writing, serving as scribes. The patients are encouraged to ask for such help if needed. Together, over a communal meal, everyone in the room will begin to form a dialogue about illness and the road to health as a community.

The Community–University Health Care Center (CUHCC), housed within the Academic Health Center (AHC) of the University of Minnesota, is located in the Phillips Neighborhood in South Minneapolis. This neighborhood is one of the first places where new immigrants to Minnesota begin their journey in America. The patient mix at CUHCC reflects this as no ethnic group makes up over 20% of the patient community and 20% of the patients are uninsured. CUHCC services include medical, dental, behavioral health (which includes therapy, psychiatry, case management, care coordination, and Adult Rehabilitation Mental Health Services)

for both pediatric and adult patients. There is also a midwifery service, dermatology clinics, and pharmacy appointments. As part of the commitment to patient access and overall well-being of the patients, CUHCC also employs domestic abuse and sexual assault advocates and in-house interpreters for our patients who speak Hmong, Lao, Vietnamese, Spanish, and Somali. Legal aid is also available through a partnership with Stinson Leonard Street, who provided about 5,000 hours of pro bono services to patients last year.

As part of a large university, close to 300 students across the professional schools rotate through the site each year. These include students in social work, medical, nursing, pharmacy, psychiatry, legal, communication, and behavioral health programs as well as those interested in public, global, and community health who are undergraduates or in various master's programs. CUHCC also serves as the main continuity clinic site for Med-Peds, a combined internal medicine and pediatrics residency at the university. For their entire four years in their residency, they come to the clinic around one day a week to learn and build their patient base, allowing a continuity of care. They also spend special months at the clinic focused on projects to improve the quality of care. Residents from Psychiatry and Internal Medicine also hold continuity clinics at CUHCC, with Pharmacy residents spending about 90% of their residency on site. CUHCC serves as the bridge between the school and community, providing healthcare to those most in need. After 50 years providing primarily health care services, CUHCC is entering a new era with a revised mission, "Transforming Care and Education to Advance Health Equity" and a new goal to integrate education into everyday practice. Narrative workshops were born out of this new direction and a push toward person-centered care. If the patient and their community is the center of education and healthcare, then it's time to integrate them into an educational setting outside the exam room. Health Centers such as CUHCC are not only members of the academic institution that houses them, but also within and born from the geographic communities where they are located. As such,

students and patients need to be at the center of education and healthcare together.

The past year, we piloted narrative health sessions. Patients were recruited from the patient advisory group, which is comprised of a group of people who have been patients at CUHCC for a length of time around two years or more and wish to help guide the clinic on patient experience. They help with satisfaction surveys, create informational materials for patients, and help bring patient concerns to the greater CUHCC administration. We have also been working to integrate them into learner education and invited them to work side by side with students to gather stories to be used in the education of health professionals, for the patients to use to see their growth, and for a possible communal book of stories about the health journeys of those living in our community. I, along with the liaison to the patients, the Mental Health Director at CUHCC, explained that the sessions were structured for those who haven't written creatively before and meant to be a way for them to tell their stories.

On that first day, while everyone sat around the table eyeing both the pizza and myself, I explained the process. We were going to go through a guided writing exercise that focused on sensory recall. I've taught Creative Writing in communities, colleges, and medical schools and developed a process that helps alleviate the anxiety of writing stories. For this exercise everyone first listed five times when they were ill. Then they chose one and gridded a sheet of paper into four sections—each focused on a different part of the senses. They had 2 minutes for each of the four senses we were focusing on and were instructed to just write, not worrying about structure or full sentences. At that point most had already stepped into their stories and we began to write them more fully.

After twenty minutes of writing it was time to talk about the experience and share. A patient read his aloud. It was about the first time he came to CUHCC, how he was referred by a neighboring clinic and how scared he was to leave the people he knew and walk into one run by white men. If his people couldn't help him how could we? The waiting room was loud with people speaking all

sorts of languages he didn't understand. However, the patient service representative (PSR) who helped him smiled. She took her time and helped him and made him feel welcome. Then, later, she recognized him outside of the clinic and said hello. She saw him as a human and, he wrote, that made him realize CUHCC just might be able to help. He was welcomed into the community. Other patients shared their stories, but none of the students or the Mental Health Director shared theirs (although they did comment that the process really got them to their story).

After this session I debriefed with the students and patients separately in preparation for the next workshop. The idea of interacting with a patient outside the clinic became a point of discussion among the students and the clinic, and this is still being discussed. Is acknowledgment or greeting someone crossing a line? The patient spoke of no dialogue beyond pleasantries; this was important to him when so many other health providers who say they are part of the community never actually acknowledge its members outside of their clinics. The medical students and a provider argued that clinical distance, that ever present idea in medicine that to preserve oneself and emotions as well as objectivity they can't get too close to their patients, extends far beyond the exam room walls. This led to a debate about how the providers in a community health center can truly be part of the community they serve within the confines of professionalism that dictates a separation.

Meanwhile, the patient advisors said they enjoyed working with the students and began to feel the community growing and having agency in that growth. The students actually heard their stories during that session and, the patient advisors said, it felt like they could work with the students to help guide health care providers to learn to listen better and help create a new breed of health care workers.

The sessions grew in size but still no students shared their stories, despite dutifully writing during the writing time. The patients, however, were ready to be heard. One man told his story about the day he was diagnosed with a Traumatic Brain Injury (TBI) at the clinic. This story also focused on the waiting

room, where he shared Bugles corn chips and talked with a man in a wheelchair. One medicine student was confused and asked about his visit with the doctor. That wasn't what mattered to the patient, though. The day of his TBI diagnosis wasn't defined by the doctor telling him he had it, but the acts of humanity, of community, that occurred before he was told. Those were moments of life; the time in the exam room was a formula he'd been through at other hospitals in the area after his accident. They were routine. The student seemed confused, but ultimately noted how important the waiting room is to the patient experience.

I asked the students why they didn't feel like sharing and was told that they didn't feel they had actually been sick. Their answers were all similar—how could their health issues in any way match those of our patients, whose health issues are so complex? The students were not only downplaying their own past illness, but also identifying the patient advisors as the holders of 'true sickness.' It seemed the students were not comfortable with their own times of sickness, partly because of their developing roles as "controllers" of illness, people who help others. Students were expressing a kind of 'us and them' in terms of who is sick or holds the title of 'patient'. While we were creating a community of those who told and listened to stories of illness, there was a divide between the protectors of those who were sick and the holders of illness.

As a bridge between academic communities and the physical communities that surround them, CUHCC is a unique staging ground. Here we were, creating a community that wasn't focused on the university within whom we were housed, but rather part of the community the center had been embedded in for the past 50 years. There is also a community of illness, one that shouldn't be ignored, with CUHCC as an epicenter. Yet, there isn't a fully realized integration between these communities. The health care students and providers who joined the sessions seemed to be taught they weren't part of the community of the ill despite the patients talking at length about how important it is for their doctors to admit to getting sick, even if the flu or a cold. There was a denial of what being sick even meant

when compared to others. Is illness, by definition, diagnosed only in comparison? How much can a provider be involved in their community while still maintaining professionalism? With the days of the neighborhood doctor who knows the ins and outs of their community gone, it seemed almost against everything being taught to suggest you could connect to the patient as a person and with equal footing in humanity. These sessions just began to scratch the surface of the ideas and complications of person-centered care as it relates to the relationship between provider and patient—and then the sessions were halted. The Mental Health Director who led the patient advisor group, a driving force in the clinic for over a decade, took an extended leave of absence from the clinic.

When there is one person who can bring half of the group together, their absence can bring work to a standstill. With the mental health director on leave, we needed a new person to run the patient advisor group and were working on a transition plan. Our director had built trust with the patient advisors and I had met with them only a handful of times, and mainly for our writing sessions. Many meetings with the patient advisors in this transition phase to a new leader for the advisors had no attendees so setting up more narrative health sessions became difficult, if not impossible.

Currently, we are working to make the writing sessions a regular occurrence for the year, and just had our first of the newly structured sessions. In hindsight, had we had a more intentional and longitudinal plan in place first rather than irregularly based on when all our times coincided, then the momentum might have stayed and the transition from the Director to someone else might have been eased. Without having a firm structure for continuation, it was easy for these sessions to stop. Also, our pool of patients was small. By expanding beyond the patient advisors we have been able to obtain a larger, possibly more consistent, group. However, this has led back to the ethical questions raised earlier—where is the professional line between clinical distance and person-centered care? Can we, as a health center, be both in and of the community? While the goal is to create this community of

stories of illness, that central idea of sitting around the table, eating the same food, and speaking on the same level is still new and at times frightening. However, with a donation of journals and new fervor (along with requests from the patients and students to continue these sessions) we hope to plan out the future and see what stories will be told next.

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Community–Academic Partnerships to Improve Hispanic Immigrant Health: Perspectives from a Doctoral Student

J. Claire Schuch

During my doctoral degree, I worked as a research assistant on a five-year National Institutes of Minority Health and Health Disparities (NIMHD)–funded study with the interdisciplinary research group the Mecklenburg Area Partnership for Primary Care Research (MAPPR). MAPPR is a practice-based research network designed to enhance healthcare access for underserved and vulnerable populations in Charlotte–Mecklenburg, NC. The core research team includes social and health scientists from the University of North Carolina at Charlotte and Carolinas Health-Care System.

MAPPR applies a community based participatory research (CBPR) approach, which involves community members and other stakeholders throughout the research process. During my time with MAPPR, I was actively involved in a study identifying the social determinants of health affecting Hispanic immigrants in Charlotte–Mecklenburg. I assisted