Dual Relationships in Specialty Care: Reflections from the Field

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Another key lesson learned was that prior to commencing the project, we needed to better communicate with the partner to identify one designated and committed staff person to be in charge of the project, to be our main point of contact, and responsible for all aspects of execution of the project. We spent a lot of time seeking input from various supervisor level staff and the executive director to negotiate the availability of the personnel, as well as the use of funding. At several times the personnel assigned to us did not know how to set their priorities. It also left us confused at times and questioning the commitment of the agency to the project.

A final lesson we will take with us for future partnerships is the need to build in more flexibility to project timelines to deal with unexpected situations, particularly when working with vulnerable populations such as refugees. For the women we were trying to engage, time was of the essence due to the urgency of trying to maintain consistent jobs. This means that the longer we took to implement our project, the more chance there was of losing participants. Due to many factors such as our inexperience in working with a refugee resettlement agency on a project of this nature, an intensive and lengthy IRB review, and the unusual pressures faced by our partner organization, the timeline for our project dragged on longer than anticipated. Luckily, due to the extraordinary assistance from our interpreter/research team member and unusual flexibility in our schedules we retained most participants. However, it is clear that in the future we need to build in the longer timeline as an expectation.

Overall, during the course of the project our partner organization experienced extraordinary change with sudden change in top leadership, engagement in a lawsuit against the state government, and planning an office move; all of which had impact on the project. In the end, we would absolutely do the project again with the same partner. We proudly worked together to share some of the photos and narratives at a local World Refugee Day event last summer. The friction that occurred during implementation faded away into satisfaction and pride in the shared accomplishment of giving voice to Congolese refugee women in our community. Moving forward, we foresee reuniting with our partner to apply our lessons learned about how to better work together as the United States moves into times of great uncertainty and potential threat to refugees.

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Dual Relationships in Specialty Care: Reflections from the Field

Lewis Raynor and Amy Penkin

Introduction

The creation of the Oregon Health & Science University (OHSU) Transgender Health Program (THP) was a grassroots effort involving transgender and gender nonconforming (TGNC) community members, local organizations serving the TGNC community, clinicians, administrators, and researchers. The THP, which launched in January 2015, offers comprehensive, affirming, and competent healthcare to TGNC individuals across their lifespan. In 2015 the THP had over 500 referrals for TGNC patients and in 2016 that number grew to over 1500 referrals.

Amy Penkin is a cisgender, LGBTQ community member and licensed clinical social worker who was hired as the THP Program Coordinator in 2015. Her duties include, but are not limited to, workforce education, assisting patients with healthcare navigation, TGNC policy development, clinical alignment of departments offering gender affirming care, and community engagement to ensure program development and services align with community needs. During the first year Amy also helped establish a THP Volunteer program to ensure the program

continued to involve the voices of the community the program was serving. That program has also created opportunities to teach TGNC individuals about how to lead trainings for healthcare settings and providers about TGNC patient needs; thus, providing jobs and revenue to a community that faces disproportionate under/unemployment.

Dr. Lewis Raynor is an epidemiologist and a TGNC community member. He works as an Investigator at OCHIN and has affiliate faculty status at OHSU where he is helping build a program that addresses the healthcare disparities faced by sexual and gender minorities. He attends THP monthly meetings where he discusses what he is doing professionally; in addition, to providing his own community–based perspective on how the program can best serve the TGNC community.

Amy and Lewis have had many conversations about the overlap in identities and relationships with regards to the THP. Amy contributed to the creation of the THP and serves now as the program supervisor, but she also is a community member with personal ties to the TGNC community of Portland, Oregon where the THP is based. Lewis is a researcher that works with providers serving the TGNC community, but he is also a community member that advocates for improved healthcare access and utilization for community members in addition, to using the healthcare system himself. Lewis' recent utilization of healthcare at OHSU forced the both of us to move beyond abstract conversations to intentional ones around the ethical dilemmas our roles with each other and the systems we work within create. We believe that the issues we raise in this essay are experienced by other individuals that work with and coexist in small communities, and we hope this work will help guide other individuals from smaller communities in their attempts to bridge roles.

Program Supervisor and Community Member Amy Penkin's perspective

The THP program has experienced rapid growth since its onset and the success of this program would not be possible without the continued involvement of and relationships among community advocates and organizations, patients, clinicians, and administrators. What I did not anticipate were the ethical issues that have arisen around my involvement in both the administration of this program and my membership in the community it serves. I have found that it is not unusual for me to engage with an individual who has overlapping personal and professional roles as a colleague, volunteer, community collaborator, friend, family member, and/or patient.

In April 2016, I was contacted by a close colleague of mine from an OHSU clinic who called to discuss a patient who came to the clinic for a consult regarding complications from a surgery received from a provider in another state. My colleague reported that the patient left before completing his appointment and appeared to be distressed, uttering a statement that was construed as a threat of self–harm. The patient's name and medical record number was provided, which led to the discovery this patient is an academic colleague, collaborator, and a personal friend, Dr. Lewis Raynor.

The context in which I met and built a relationship with Lewis was collegial and often informal. I knew he had encountered barriers to navigating healthcare; however, we never discussed those barriers in regards to his current utilization of OHSU healthcare services. He discussed personal healthcare experiences that are common to TGNC members, and we saw our discussions as a larger dialogue about creating a program that addressed those barriers and fostered trust between the provider/healthcare system and the patient. Our relationship was never based on him being in crisis.

After the clinic contacted me, I accessed Lewis' healthcare record and contacted him. We had a conversation where I let him know why I was reaching out and the professional capacity in which I was calling him. I directly asked if he was at risk and if he needed help. He let me know that he was not at risk, and I took him at his word, as we had established mutual trust in one another.

Later I reflected upon how my relationship with Lewis informed many elements of this interaction, for better and for worse. In the context of this crisis call, I was vulnerable to underestimating Lewis's true level of distress, as I relied on my knowledge

of him as a friend and colleague. I knew personally that Lewis was having complications and seeking care at OHSU; however, he had not asked for assistance navigating that care, nor had I considered the ways in which I could be intentionally or unintentionally involved in his healthcare. I had not anticipated that I would be accessing my colleague–friend's medical record and documenting my assessment and conclusion.

Since this encounter the THP has hired a second employee who is also a social worker, which gives us greater flexibility around assigning an individual to meet patient needs, but this individual is also another member of the LGBTQ community in Portland. These dual relationships are the underpinning by which the THP functions, as it would be much more difficult to build trust with the community accessing the services and the community helping create and guide the program if the program were staffed by individuals that did not have a connection to the community being served.

Since April I have spent time reflecting on the countless individuals with whom I've worked with in more than one capacity but it was this particular interaction with Lewis that propelled me towards a change in my practice(s). I have become much more proactive in addressing and discussing roles, relationships, boundaries and privacy with anyone who has the potential to access healthcare with the THP.

TGNC Community Member and Healthcare Researcher Lewis Raynor's Perspective

In an era of emerging transgender health programs and expanding care options there remains a dearth of healthcare providers serving TGNC patients in the United States. Patients often travel far from their homes, if not internationally, to access healthcare and obviously their support systems cannot travel with them. When they return to their homes to recover, they lose access to their healthcare providers. It is an unfair and unreasonable burden for patients, and their caretakers, and presents a questionable ethical landscape for providers who send physically vulnerable patients across the country to recover without ensuring there is connected care.

My healthcare took place outside of the state in which I reside. I'm incredibly fortunate to be employed, to have insurance cover my transgender related healthcare needs, and to have the resources to pay to live out of state to receive medical care if necessary. However, my care is fragmented and largely driven by own well–developed knowledge of healthcare systems and my ability to advocate and oftentimes drive my own healthcare.

In April of 2016 I underwent a procedure in another state. Before I left that state I knew something was wrong. Fortunately, my relationship to the THP and my PhD in a healthcare field grants me both the awareness to know that I needed to get help and who I should contact in my state. In fact those relationships were formed by my involvement in the THP at OHSU. Consequently, I was able to contact a THP affiliated healthcare provider, discuss my concerns, and access care. I had very serious medical complications that necessitated surgical repairs and multiple hospitalizations.

The emotional burden of being a member of the TGNC community is sometimes beyond comprehension. We as a community fight for healthcare access and are frightened to push for measurement of how that healthcare is performing. We exhaust bank accounts and connections to physically get to the care we need. We sit in silence with our complications because we are afraid to talk about them lest we lose access to any care. We sit in silence with our complications because of the transphobia that makes us fearful to ask for support from the people in our lives that are not a part of our community. We sit in silence because we are scared.

It is that fear that I was steeped in that day in April. I had devastating results from my complications. I was struggling with how to take time off of work to recover, as I had fought for three years to find a job in my field after transitioning. I struggled with how to walk into another provider's office and trust them with my body. I could not do it that day. That is what I expressed to the front desk staff at the clinic, and I think that they did the correct thing by calling Amy.

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)