We Really Do Have the Same Goals: The Push and Pull of One Community–Academic Partnership to Support Congolese Refugee Women

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caregiver and older adults in every story. An aspect of the study that I did not anticipate, and fuels the research partnership we now have, is the lack of understanding of the Amish culture from Western healthcare providers. Every story had an aspect of cultural miscommunications, financial or transportation based barriers that was not appreciated. This information made me realize that there is still so much I don't understand.

During this period I became pregnant, my parents retired and my personal caregiving role began to shift. Normally you might think that these personal events might complicate the research relationship. However, because of the unique opportunity partnership with a community can have, my research partners are more than my research participants. We have more than an exchange of data and forms. In alignment with a key principle of participatory research, a sense of mutual growth pervades our research and our personal relationship. Several of the older adults who were being cared for during data collection passed on during the study, and I was grateful to be included in their funerals. My son enjoys the friendship of other Amish children born during the same time period, and I have new insight into the changing role of parent and child, as my own parent's age. I did not anticipate how much engaging in this partnership would affect my own life. I am humbled to be in this research relationship and I am grateful that I can do this work with this community.

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We never expected a mundane conversation about university curriculum to blossom into a community based participatory research endeavor. However, looking back, it seems natural that an international relations faculty member who had worked with a refugee organization for years and a public health faculty member who used Photovoice research with vulnerable populations found common ground. The main purpose of our project was to assess the needs of Congolese refugees coming into Indianapolis in order to improve the ability of refugee resettlement agencies and public policy makers to provide effective and, culturally appropriate services. Photovoice methodology was intentionally selected to give the women voice through the photographs and subsequent storytelling sessions, thus making them active participants in the study and providing a firsthand view of needs in their immediate environments through photos. Our initial conversation led to envisioning a Photovoice project with refugees, acquiring internal funding, securing an external grant associated with state public health funds, and utilizing Photovoice to understand perceptions and experiences of health and integration among Congolese refugee women living in Indianapolis.

Our community partner was a non–profit organization dedicated to refugee resettlement. From the outset, we strived to engage them in all facets of the project including choosing the specific refugee subpopulation, formulating research questions, recruitment, and implementation. We approached our partner with the idea of using Photovoice to better understand integration and health of refugees and asked two questions: 1) Is this something of interest and utility to you? 2) If so, which population of refugees do you feel would be most helpful to conduct Photovoice with? Their answer was yes and people fleeing the Democratic Republic of Congo,

Iraq and Syria were prioritized by the resettlement agency due to those being new refugee groups in the state.

We agreed the focus would be on women primarily due to alignment with an existing women's program at the agency.

Our partner was particularly excited about the use of Photovoice methodology to engage and give voice to refugee women, particularly the newer groups like the Syrians, Iraqi and Congolese that they had limited experience in serving. One curve ball that occurred was restriction of the study population to Congolese refugees only due to the funding agency's application of the U.S. Office of Management and Budget (OMB) definition of ethnic and racial groups. The OMB considers Iraqi and Syrian women as Caucasian and therefore do not count as minorities and had to be excluded from the study. This is a case where the OMB definitions were not helpful in serving the greater needs of refugees or refugee resettlement agency and all parties involved were dismayed about the shift in our project.

Initially, external funding was secured in close collaboration with the former executive director. During the course of the project, that initial executive director left the agency, so it was inherited by the next executive director. Later, we worked closely with two assigned personnel to flesh out the details of the project including working with our university's Institutional Review Board (IRB). Since we applied for the funding together, the amount was split between us, with the majority going to our community partner. The funding was limited in that it did not pay for our time as researchers, but simply for materials and supplies to conduct the project. This becomes relevant because we engaged in conducting the research in addition to our regular teaching and service responsibilities as opposed to buying out any time for the project.

One of several positive aspects of this partnership was generous investment of the community partner in terms of human resources, space, and transportation resources. They assigned their sole medical case manager to work as an interpreter for the Photovoice project. This was written into the budget, but in the end she invested more time than she was compensated for. She was an invaluable resource as an insider of the community, ability to speak several languages and as a critical bridge in helping us recruit and retain the participants. It was also wonderful that we were able to use the space of the community partner to hold initial interviews. Additionally, the partner used their connections to find another, third partner to donate community space close to the homes of most of our participants where we held all Photovoice sessions. Finally, the partner provided their bus to transport participants to and from Photovoice meetings. This was instrumental for maximizing participation since the women did not have to rely on public transportation.

While we agreed in principle to the common goal of serving the refugee population, we faced multiple challenges. We differed throughout the project about the level of priority and significance of the project for the community partner and the women, lack of clarity in the point person with the partner institution, and appropriate use of funding. Though the new leadership appeared to be on board with the project, we felt the commitment to and context of the project was not sufficiently conveyed to staff assigned to work with us on the ground. We endeavored to communicate what we perceived as the relevance of the project for the day–to–day work of the agency, but we often missed the mark.

Sometimes, we felt perceived as stereotypical, leisurely academics conducting research. Other times, it appeared our partner personnel felt grudgingly required to help us out. They would not hesitate to ask us to wait if they had other work and sometimes changed appointment times and days at the last minute. Our perception was that the partner was not taking the project as seriously as us, viewing it as *our* research rather than a joint project. At different points, we were told that the project was taking too much time and commitment. This was disappointing to us because we thought the participatory process through which the agency had agreed the project was beneficial and had originally selected the priority population was evidence of their commitment. On the other hand, it seemed our community partner felt that

we did not sufficiently understand the day to day pressures of a non profit organization. While the project was important to them, serving their clients on a daily basis and dealing with emergency situations was clearly, understandably, their priority. A project that would help their clients in the future, therefore, could wait.

There were multiple challenges throughout the project that served as "ah ha!" moments and lessons learned for future work with partners. One such challenge was lack of a central point person from the partner agency. It was originally the "baby" of the first executive director who left for another organization before the project got off the ground. While the new director was interested, there suddenly were multiple things to manage such as adapting to the new position, and therefore, attention was clearly diverted. The previous executive director had committed to be the main point person, but the new director could not focus on the project in the same way. We were assigned two different personnel to work with us, an intern familiar with Photovoice and their medical case manager who was also an interpreter. The intern lived in another city and was available just two days per week and the health navigator had to divide the responsibility between what she saw as her "real job" that she was paid for at the organization and the research project, which felt like extra work for her. This meant that she was often unavailable and did not hesitate to back out if she had other commitments. Though the agency received funding to support part of her salary while assisting with the project, the intense time period of work for the study occurred on top of the regular workload and she justifiably, felt overworked. While we kept ourselves flexible outside of our regular university responsibilities and schedule, it became frustrating to constantly negotiate her availability with her or her supervisor. It was not clear who our point of contact was in the organization.

We felt that partnership implied a commitment from our community partner but our sense was that they were doing us a favor by partnering with us. This became apparent from the way the assigned personnel dealt with us as well. There was friction at different points due to their assumption that we did not know how to interact with refugees and unnecessary negotiations about resources like access to the bus, availability of drivers, or delivery of food without checking with the leadership structure. In frustration and trying to stick to a tighter timeline, we sometimes went to the leadership or executive director to get what we needed, which in turn led to more friction. We addressed this through conversations with the agency leadership and felt encouraged by a change and more amiable interactions during the remainder of the project. The assigned representatives from the resettlement agency became much more responsive and respectful of our requests regarding the project.

One major lesson learned was that we need to better communicate in advance about how both parties plan to use grant money. Our understanding was the agency would hire an additional interpreter or personnel. The community partner, like most nonprofits, wanted to use the grant money as an additional resource to support the organization. As a result, no new personnel were hired to assist with the project. Existing employees had to handle both their assigned work and additional work of the project. Therefore, for the duration of the two months that the project lasted, they were constantly torn in different directions. The organization did not want to pay them overtime, so there were restrictions on how many hours they could work. The employees wanted, and we felt they deserved, time off or extra pay to do the extra work for the Photovoice project. When they got neither, there was resentment towards us and the organization. We learned to keep in mind that for nonprofits, funding is always an issue and therefore, they are always going to be strategic about spending money. This means that it is up to us to ensure that we have a clear idea of how much time and commitment our project will require and convey it to our partner institution. We did not know how much time the project might take and therefore did not sufficiently communicate to our community partner how much time and resources the project might require. This led to the partner being overwhelmed to some extent by the obligation of the project.

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