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must be maintained. Learning to dance is an art, not a science!

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Personal Narrative

Gelassenheit. The first time I heard this word it sounded like a sneeze and I remember asking for the research participant, who I was interviewing, to translate. She paused, appeared thoughtful and said "for you it would be, it would be you being humble. That what you do is for God and you are grateful you can." When I decided that I wanted to pursue doctoral education in nursing research almost ten years ago, I had no inkling how much this word, and my relationship with an Amish community would enrich my life. I knew that I wanted to do research with a population who was vulnerable. I knew that I wanted to learn how to listen to people's stories and translate their perspective to the scientific community. I did not grasp how much I didn't understand, and how reliant I would become on partnership to guide the research. My personal experience taught me that thinking you are humble and grateful, is not the same as being humble and grateful.

Research with groups who are considered minority, vulnerable, ethnically or racially diverse is a unique experience. There is a wealth of research about how the research community should interact with these groups, all mindful of a less than savory history of how these groups were marginalized during the research process. When I first approached a member of an Amish community I knew this history, and I thought I was sensitive to the power differential. I assumed that as long as I was polite, there was no reason that they wouldn't want to work with me.

I read literature about working with cultural groups, and most said to begin with a female Elder. When I first approached a female Elder of the Amish community about doing a research study, I asked her whether she thought there would be people in her community who might want to talk to me about mental health and aging. She was very polite and encouraging at the time, but never returned subsequent messages and when asked directly was evasive about getting started. I reflected that this may not have been the best strategy. This was the first of many missteps in my research relationship with this community that I made from a paternalistic and naïve perspective that of course they would want to talk to me, of course they would want to understand the same things I wanted to understand.

My second attempt met with more success, because instead of just asking someone I knew who was Amish, I asked who I needed to talk to, and how I should talk to them. This male Elder of the community was also polite and encouraging but blunt in his opinion that, "no, no one will talk about that". I was distressed. I hadn't planned on him saying no. In the moment I was faced with a choice, walk away, and be thankful for his time or see if there was another way. I asked him what he thought people would want to talk about. Instead of giving me an answer, he told me a story. He told me about someone in the community who had taken their grandmother to the hospital because she was experiencing dizziness. He said that the hospital doctor ordered multiple medical tests and kept her in the hospital for several days. He shared that this was hard on her family who had to hire a driver to take them back and forth to the hospital, over 30 miles away. They were worried about the cost of the tests and the hospital stay, but wanted to help her. The grandmother had been sent home

with a diagnosis of syncope and instructions to stay hydrated, make position changes slowly, and no reason for why she was dizzy. Her medical bills were several thousand dollars.

Over time I would learn why these details were important to the Elder and why he wanted me to understand why this is something people in his community would want to talk about. That day I asked him to consider being my partner in a research study. He agreed and that was the beginning of a community based participatory research relationship. Over the next four years, myself, the community Elder, and his wife and 13 additional research participants would work together to explore the question "what is the lived experience caring for an Amish older adult and your interactions with Western healthcare providers".

After those initial missteps, I was more cautious in my interactions and sought practical, real–world advice from my faculty with expertise in community partnerships. I recruited colleagues with experience doing research with Amish and Mennonite communities, and when unsure, asked the Elder and the participants themselves for direction. This attitude reflects the concept of *cultural safety*, where the research participant is the expert of what is or is not culturally safe. In other words, I gave as much power as possible to the Amish people I talked to, to tell me what I could say, what I should ask, and what I should think or understand about them. I moved from a place of polite interaction to real humility and gratefulness. Every interaction became an opportunity to learn, to listen to understand without trying to follow a textbook or my own assumptions.

Subtle differences in time orientation, level of comfort with geography, gender roles, and the value of food would influence every aspect of the study. For example, depending on which Amish community you are in, there may or may not be phone access in the home so messages are left on a community phone and may take several days to receive. Finding an Amish home in the dark, in rural area, where you have not been before, without the aid of a google mapped address, meant stopping and asking for directions, and learning to navigate by unusual directions such as the third white barn on the left or past the turn off for the "*Smiths*". One day when I arrived to see the Elder, he appeared to be frustrated with me. After some awkward conversation he asked me "why didn't you take your husband's last name". I was not prepared to answer this question and immediately was concerned that my feminist preference would offend him and that this meant the study was over. I paused and considered what was true and what he might understand. I told him that I liked my maiden name, that my father was one of the most important people I my life, and as his only child with children, I wanted to preserve his name. I shared that changing your name while a student meant lots of paperwork with the University but I loved and honored my husband very much. He paused and laughed, "paper work, you *English* (Amish term for non–Amish) like paperwork". He still teases me about this but somehow my answer was accepted and the study and our relationship continues. Every meeting with the Elder, every interview, and every interaction with the research participants from developing the questions, to the actual interviews and follow up interviews, and the analysis of the data involved food. Particularly sweets and home brewed mint tea. I learned to arrive hungry and bring my own contributions to these meetings. I learned the value of food as an ice breaker, how it binds us across differences in culture, age, gender and power differences. The time spent sharing food taught me to relax and enjoy the time spent talking about shared interests, listening to their stories with an open heart and mind, careful to ask for clarifications when I didn't understand, when I needed translation of the low–German or Dutch words that would slip into their stories.

The research study took over four years to complete and during that time we all learned from each other. I was able to share with the Elder and his wife research done with the Amish in other Amish communities. Several participants showed me ways that they care for their Elders in the home without modern conveniences. The study revealed the significance of the Amish cultural value of *Gelassenheit* and how the spirit of humble sacrifice and love infused the relationship between

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

Jyotika Saksena and Shannon McMorrow

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,