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Research With Refugees and Vulnerable Populations in a Post-COVID World: Challenges and Opportunities

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At the Stress, Trauma and Anxiety Research Clinic (STARC) at Wayne State University in Detroit, we are currently amid data collection for a longitudinal prospective study of Syrian refugee children and their parents. Funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, our goal is to understand the impact of exposure to war trauma and the stress of migration on symptoms of post-traumatic stress disorder, anxiety, and depression, as well as the neurobiological, epigenetic, and environmental correlates of risk and resilience. Like many research groups around the world, the COVID-19 pandemic brought our work to a screeching halt. Researchers who, like us, were engaged in human subjects research were left grappling with the question of how to continue their work while ensuring the safety of both research staff and participants, and while maintaining scientific integrity. In March 2020, our institution halted all in-person human subjects research that did not have direct benefits to participants, which continued until October, when research activity was resumed subject to implementation of modified procedures. Over the past 2 years, we have pivoted, adapted, and flexed, ultimately making changes that have allowed us to continue successful data collection throughout the pandemic. This article will discuss the specific challenges of working with ethnically minoritized and immigrant populations during the pandemic, the adaptations that we implemented to enable safe and effective data collection, as well as the new knowledge that we can apply to future research protocols.

BUILDING TRUST WITH MINORITIZED POPULATIONS THROUGH CULTURALLY SENSITIVE RESEARCH PRACTICES

We first recruited families to our study in 2016 to 2017 upon their arrival in the United States, and our early findings are published in this journal¹ and elsewhere.² During the first

wave of data collection, we partnered with a local nonprofit agency that provides social services, medical care, and health screening for refugees. Families were first introduced to the research opportunity by their physician, who was of Middle Eastern or North African (MENA) origin, during the mandatory physical health screening that occurs within 1 month of arrival. More than 90% of refugees referred to us agreed to participate in our research—an impressive figure that we attribute to the introduction of our team in the context of a trusted community organization, and by an ethnically and culturally informed physician, resulting in transfer of rapport to our research team. Based on this successful recruitment approach, we have since expanded our network to include relationships with a variety of community partners, including local mosques, schools, and nonprofit organizations that provide support to the MENA community in Detroit. These relationships may be particularly important when working with refugee and immigrant populations whose immigration status makes their residency rights precarious, particularly in the context of anti-immigrant government policies. This environment may render families reluctant to engage with research or medical institutions because of fear of deportation.

From the outset, our data collection team was intentionally established by the principal investigator (PI)—himself an immigrant from the Middle East—to primarily comprise bilingual and bicultural researchers, some of whom are also refugees, or the children of refugees. Our data collection team is led by a physician of North African origin, who is the primary point of contact for our families. His occupational status, fluency in Arabic, and knowledge of MENA culture mean that he is highly respected and trusted by our participants. The practice of ethnic and cultural representation of our study population in our research team has likely facilitated both our recruitment success and participant retention.

A study conducted by Kira *et al.*³ measured the internalized stigma of mental illness in Arab, majority Muslim

populations, and found a prevalence of 84.9%. As internalized stigma is the most significant barrier to accessing mental health services because of the shame of disclosing personal and family issues to outsiders,⁴ we were aware that our target population might be reluctant to participate in our study. Indeed, in addition to asking about mental health symptoms, some of the questions that we ask are of a deeply personal and often inherently stressful nature (eg, war exposure, forced migration, and other traumatic life events); therefore, our research team must work with cultural awareness and sensitivity to build rapport and trust with our participants. During research visits, we routinely gender-match research assistants to participants, and when asking particularly difficult questions (eg, about experiences of sexual abuse), we do so only at a time in which privacy from family members is ensured. If requested, we also accommodate the need for the father of a family to be present in the home, often necessitating evening and weekend work. Although these considerations can present logistical challenges and necessitate flexibility from our team, the specific attention to culturally sensitive practices during our research visits is particularly important, as minoritized communities are more likely to have experienced medical abuses and/or research exploitation in the past.

The solid foundations of trust and mutual respect that had been built with our research participants likely contributed to our ability to maintain our connection to them when the COVID-19 pandemic began. We now know that the effects of the pandemic are not shared equally across demographics, with vulnerable groups—including the ethnically minoritized, high-risk, and low-resource population with whom we work—being more adversely affected,⁵ further compounding other postmigration stressors encountered by refugees, such as financial insecurity, discrimination, and social isolation.⁶ In 2020, Ramadan began in late April, which coincided with a month-long extension of the State of Michigan's stay-at-home order. Ramadan is one of the holiest months in the Muslim calendar, characterized by families gathering around shared meals and observed by most of the participants in our cohort. We were aware that this might represent a particularly isolating time for the families in our study. Thus, our team put together and delivered care packages containing school supplies and children's snacks to our participants' homes, offering practical and emotional support. This helped strengthen our connection with the families, deepening the long-term trust between our research team and members of the community with whom we work.

We were also aware that, during the pandemic, our study participants were likely experiencing heightened stress from economic insecurity, health concerns, and ethnic inequity,⁷ without the usual buffer of social support,⁸ while

at the same time balancing additional responsibilities such as homeschooling children. Participating in research may therefore have imposed a greater burden than normal. Consequently, we paid extremely close attention to our data collection practices, ensuring that we minimized the research burden. We carried out interviews at times of day that were most convenient for participants, including evenings and weekends, to capture after work and school hours. Our team also conducted a substudy examining the impact of the pandemic on our cohort.

PROVIDING TECHNOLOGICAL RESOURCES AND SUPPORT TO AID IN THE TRANSITION TO VIRTUAL DATA COLLECTION

Prior to the pandemic, our data collection procedures involved home visits, at which we would assist the families as they completed questionnaire packets and provided biological samples. When in-person data collection stopped, we shifted to entirely virtual visits. Our revised protocol entailed first calling the families to obtain consent for remote data collection, then delivering a tablet with pre-paid Internet access to conduct video calls with the children in which we asked them the survey questions; parents completed paper copies of questionnaires that were either mailed or dropped off at homes, asking us only when they needed guidance; saliva sample kits were mailed or delivered to mailboxes/porches; and we used the video-conferencing software to guide participants through providing a sample. We also transitioned to using REDCap, a Health Insurance Portability and Accountability Act (HIPAA)—compliant secure Web application for building and managing online surveys, to ensure that our data collection and management were streamlined and accurate.

This rapid transition was not without challenges: training the research team included multiple practice runs to fine tune and problem solve before we felt confident that the transition could be executed smoothly with participants. Some groups have reported that video visits increase the workload of research staff because they need to attend both to the data collection as well as to technology-related tasks.⁹ Our experience was that, provided that the Internet connection was high quality, we were able to communicate in much the same way as in an in-person visit, and minor technical problems (eg, difficulty hearing each other, or when the video feed froze) did not cause major disruption, as our team was trained to competently troubleshoot. Of course, different levels of technical support are needed for different people; less technologically literate participants needed more support, which our team was primed to detect and offer. As many of our participants live in underserved urban areas where access to technology—including suitable devices and

Internet bandwidth—was a barrier, we adopted the practice of physically delivering our own tablets to each family with pre-paid Internet access. We ensured that we used Internet services with the best coverage in the specific urban areas where our participants live. We also always provided devices that were fully charged to avoid any expenses being incurred by our participants needing to use their own electricity to power these devices, to prevent any additional economic burden being placed on our participants.

INCORPORATING RELATIONSHIP BUILDING AND IMPLEMENTING PRACTICES FROM TELEHEALTH INTO VIRTUAL RESEARCH

Another difference from in-person visits has been the social interaction that occurs naturally upon arrival at participants' homes: exchanging greetings, being invited inside, and being introduced to each family member. These informal prosocial activities serve to put participants at ease and help to build rapport, which is especially important in longitudinal research for limiting attrition. Accordingly, these activities were important to incorporate at the start of a remote "visit" despite the absence of the physical cues to prompt them; each research assistant would re-introduce themselves at the beginning of the video call and exchange greetings with the child and their parent; inquire about daily life topics such as how their day had gone, or school. These types of activities may have even greater value when working with participants from interrelated cultures who have deeper traditions of social formalities in which establishing trust and building relationships are more important.¹⁰

Many of the considerations described above also apply to the delivery of clinical care via telehealth.¹¹ Our team benefited from being based in a department of psychiatry that already had an established infrastructure for delivering telehealth in disadvantaged communities in and around Detroit, and being led by a PI with considerable experience in delivering psychiatric care remotely. The team was therefore familiar with the challenges associated with working in a virtual modality with an underserved population, and were able to anticipate these challenges and overcome them. Considerations included the need for adequate training of research staff to be able to use the technology appropriately; devoting time to ensuring that research participants were comfortable with the technology; ensuring that technological barriers were limited by delivering fully charged devices that were set up with all required software and good Internet connectivity; and, by knowing the importance of devoting time to ensure the comfort of our participants at the beginning of a session—building trust and rapport through social interactions. These considerations, albeit important in

conducting virtual research or clinical care with any population, may have heightened significance when working with marginalized communities who are more likely to do the following: (1) to live in underserved areas; (2) to face socioeconomic barriers to participating in research; and (3) potentially to have had experiences that resulted in cultural mistrust with research or medical institutions.

RECOGNIZING OPPORTUNITIES FOR RESEARCH PRACTICES IN A POST-COVID WORLD

Opportunities also arose from this evolved research protocol: we found that the data that we obtained had fewer missing values, which we believe stems from adult participants now filling out questionnaires on their own and at their own pace, instead of being asked questions by a researcher during a time-limited home visit. Another opportunity was the increased time and cost efficiency gained through our ability to conduct several remote data collection sessions simultaneously rather than needing to travel to interviews and provide transportation for staff to visit each home. Furthermore, any safety concerns for our research staff visiting private residences were eliminated, enabling a single member of the research team to conduct a study visit. Our newly adopted virtual data collection measures also helped more time-strapped undergraduate and medical students join our team because of the flexibility that working remotely afforded them. Clearly, reduced geographic barriers to participating in research can benefit participants as well as research staff; although our sample is all located in southeastern Michigan, remote data collection practices have the potential to make participating in research more accessible to people living in rural areas (notwithstanding limited access to technology), expanding our reach beyond metropolitan centers. Such opportunities once again resonate with those seen in clinical practice, with telemedicine being made available to populations with limited resources and in geographically distant locations. In much the same way as telehealth has the potential to increase equity of health care provision, remote data collection practices have the potential to promote better representation of marginalized communities by reducing socioeconomic barriers to participating in research, such as lack of transportation and the need to take time off work and to arrange childcare.

CONCLUSION

At the time of writing, we are able to conduct in-person research (with safety protocols in place), but our recent experience of the Omicron variant of COVID-19 means

that we remain aware that new restrictions to minimize the spread of more transmissible or virulent variants of the virus may be imposed in the future. Having successfully incorporated remote methods of data collection into our standard repertoire of research protocols, we are now confident that any further restrictions will not impede our work, and we continue to offer the option of remote visits to any participant who is more comfortable with that modality. For many persons, remote interviews are a welcome alternative, and we anticipate that this trend will continue as the population at large becomes increasingly comfortable using online tools. We have retained almost all of our study participants and have continued to answer important questions about the effects of war trauma, forced migration, and resettlement on Middle Eastern families.

Our experiences detailed above of conducting longitudinal research with Syrian refugee families highlights the importance of understanding the sociocultural context of the population within which research is conducted, and paying special attention to building enduring and trusting relationships with the community. These considerations may become even more important during times of exaggerated hardship, such as during the COVID-19 pandemic. By purposefully engaging and working closely with nonprofit organizations serving refugees, we have not only had access to recruitment resources but have also benefited from the relationship of trust that these organizations had already built with the people whom they serve. In our view, this foundation of trust contributed to the comfort of participants in engaging with the research team and enhanced their ability to share even the most sensitive information during research interviews. Furthermore, by using research personnel who share the same cultural and language background as the study population, it is possible to better overcome the mistrust that can exist between marginalized populations and research or medical establishments. Moreover, people who share the same culture or even life experiences with refugees might be better able to see the limitations and opportunities of research designs, allowing more thoughtful approaches to the questions asked and the ways in which they are asked. The quality and integrity of the data collected is likely also to be positively affected by these practices. Importantly, incorporating the strategy of representing ethnically minoritized or vulnerable populations within research teams has the

significant additional benefit of contributing to diversity, equity, and inclusion in the field of psychiatric research.

The ability of our research team to quickly pivot to remote data collection at the onset of the pandemic relied in part upon its understanding of the sociocultural context of how the pandemic was experienced by our participants, as well as the potentially limited resources available to them in a time of hardship. Finally, applying the knowledge gained from the provision of clinical care via telehealth to underserved and minoritized populations—a field that is more advanced than the provision of teleresearch—is also of significant value as the research community incorporates virtual research protocols into standard research practices. Adaptations that were necessitated by the pandemic have challenged us to incorporate technology effectively into our research, maximizing the efficacy of our data collection strategies and minimizing barriers to participating in research. While presenting challenges, these adaptations have ultimately provided us with advantages that we will continue to adopt as the threat of the pandemic recedes.

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