Practical approaches to conducting biopsychosocial research with refugee and internally displaced communities

A B S T R A C T

Refugees and internally displaced people comprise one percent of the world population. Forced migration involves a multitude of ongoing stressful and traumatic experiences, often resulting in lasting psychological symptoms for people resettling as refugees. Despite these risks, the underrepresentation of refugee populations in research—particularly in biological sciences—has impeded the allocation of effective resources and the development of novel interventions for these groups. This paper identifies and addresses key methodological challenges to successfully and appropriately conducting research with refugee and internally displaced communities, many of which have served as barriers to improving research representation for these populations. Methodological challenges discussed include language and literacy barriers; political fears; differing cultural dynamics between participants and researchers; and others. We provide practical recommendations for overcoming each challenge, often sourced from our experience conducting multi-year studies and interventions in refugee mental health. Several key strategies include the recruitment of researchers and research assistants from similar cultural and linguistic backgrounds as participants; providing detailed, ongoing communication about informed consent; avoiding assumptions regarding participants' understanding of concepts that may vary based on culture or experience (e.g., "voluntary" research; confidentiality); and adopting flexible data collection procedures compatible with participants' needs and restrictions. Finally, we discuss the role of the researcher in regard to cultural competencies and partnering with the refugee community. Given the increasing global population of refugees, the strategies discussed in this paper are suggested in order to encourage future research in this underrepresented population and empower investigators to logistically carry out studies with refugees.

1. Introduction

The experience of forced migration involves a unique, often highly stressful series of events, typically beginning with war or disaster and followed by dissolution of community, loss of resources, high risk of stress-related disorders, financial uncertainties, and social or cultural isolation [1–3]. Despite the growing global population of forcibly displaced persons, estimated in 2020 to comprise 1 % of the world's population [4], refugees remain widely underrepresented in psychiatric research [5]. Though significant insights have been gained in recent years, the research available remains sparse when considering the substantial and complex psychological burdens faced by the refugee community. Not only are these groups likely to have been exposed to traumatic events such as war, explosions, physical or sexual assault, torture, or loss of loved ones, but they also commonly face unique stressors related to migration and resettlement. Discrimination and harassment; insecurity of basic needs (e.g., food, shelter, health care); isolation; lack of social support; downward socioeconomic changes; acculturative stress; language barriers; financial and job uncertainty; and disruption of traditional or cultural family roles are among the multitude of chronic stressors displaced persons face—often continuing long after resettlement in a host country [6,7].

The unique and often chronic nature of stressors experienced, differing types and severity of trauma exposure [8], and diverse genetic and ethnic backgrounds may influence both biological and psychological symptom presentations [5]. Variation in cultural backgrounds, as well as their intersection with the acculturation process in a host country, also contribute to unique experiences across refugee groups and individuals [9–11]. Accordingly, patterns of psychopathology development and treatment outcomes for refugees may differ from those observed in other populations, making population-specific research necessary to improve support and outcomes for refugees. Furthermore, while most trauma and stress related research is done in civilian and military populations, refugees consist of a unique group of civilians with possible military trauma, along with chronic stressors of urban civilian populations.

Considering these dynamics, available data for refugees remains proportionally limited. Research with refugee children is particularly lacking, as is longitudinal data that could improve predictive insights into symptom trajectories and the development of psychopathology. The discrepancy in available biological data is especially vast: despite significant advances in our recent understanding of neurological, endocrinological, and psychophysiological mechanisms of trauma and stress, most studies of this nature have been in Western populations [5]. By

Table 1

Challenges and strategies for conducting biopsychosocial research with refugee communities.

Challenges	Recommended Strategies
Challenges related to navigating cultural differences	Clearly explain protocols, confidentiality, and anonymity of data using lay terms and examples
	Conduct psychometric validation studies in diverse cultures and populations
	Ensure measures, procedures, and instructions are provided in an appropriate language
	Make efforts towards collaboration and co-publication with in-country scholars (e.g., initiating contact via email, social media, or at conferences; remaining informed on work released by other scholars in the field)
	Offer several language options and comprehension methods for survey completion
	Openly encourage questions
	Partner with in-country stakeholders and organizations (e.g., in-country scholars, religious leaders, schools, social services, public/local social media groups, medical care centers)
	Recruit researchers and research assistants with language and cultural fluency
	Support rapport and trust-building through awareness of cultural factors (e.g., some participants may prefer working with researchers of the same gender)
	Use measures that have been tested and validated and feasible procedures for a given population
Family dynamics regarding decision-making	Allow parents or guardians to collect biological samples from children when feasible
	Obtain informed consent from all appropriate family members
	Recruit both male and female research assistants to account for participant comfort level (e.g., mothers and children may prefer female researchers)
	Use culture-specific knowledge regarding who must be involved in decisions to participate in research
Lack of trust sharing sensitive information	Begin rapport-building immediately (at initial meetings)
	Continue fostering rapport across research process by sharing findings with communities, local scholars, and in-country organizations
	Emphasize the voluntary nature of the research
	Explain how the research aims to benefit immigrants, refugees, and their families to build a mutually beneficial alliance
	Focus on prioritizing participant comfort and practicing ongoing informed consent procedures
	Maintain consistency by having the same researchers or research assistants involved in recruitment also conduct data collection
	Offer data collection activities via phone or online for participants wishing to remain anonymous
	Offer private rooms or at-home visits for in-person data collection
	Partner with community organizations and in-country stakeholders already working with refugees to build a network of trust
	Provide detailed explanations of how information will be kept confidential and data storage protocols
	When feasible, allow participants to collect biological samples at home and submit by mail if desired and feasible based on location/infrastructure
Political fears	Assure participants that research activities will not impact their legal status
	Avoid collecting data on legal status
	Be aware of how participants' racial and ethnic backgrounds may impact their experience in a host country
	Be aware of local, regional, and national laws and political climates that may impact sense of security for refugees
	Describe data security procedures in detail and encourage questions
	Describe in detailed, layman's terms how and where collected data will be disseminated
	Explain any social justice aims of the research and how findings may benefit their community
	Inform participants that lack of participation will not negatively affect their immigration status
	Offer the option to remain completely anonymous
Research challenges related to logistics of migration and resettlement	Collect multiple forms of contact (e.g., phone, email, social media apps commonly used by participant group, contact info for other family members)
	Ensure initial contact with recruitment materials is positive, culturally sensitive, and non-coercive
	Form relationships with community organizations that work with refugees and keep databases of contact information
	Obtain IRB approval for multiple forms of recruitment
	Offer easily accessible data collection spaces, such as in participants' homes, schools, or health clinics
	Provide flexible schedules when inviting participants to a lab space
	Provide online options for filling out surveys and consent forms
	Use portable or mailable biological data collection options if feasible

contrast, most studies in refugee populations have been limited to epidemiological and psychopathology data, using self-report as the primary unit of analysis.

Notably, extant data provides strong support for neurobiological research in diverse populations, including refugees. For instance, despite their possible utility as inexpensive, accessible biomarkers of psychopathology, psychophysiological biomarker studies are scarce in refugee populations [5]. Those studies that do exist have found differential results among refugee groups and healthy controls, including higher heart rates in Iraqi refugees (regardless of diagnostic status [12]); and reduced auditory and visual response during information processing in refugees diagnosed with PTSD, as compared to controls [13]. Pro- and anti-inflammatory cytokines have also been investigated as candidate biomarkers, with most of the literature indicating a positive relation between inflammation and severity of trauma-related symptoms [14, 15]. Notably, this association has not reliably emerged in refugee populations to date [16–19]. While biological differences in part may be explained by ancestral variation in immune-related genes [20], the lack of genome-wide data for non-Western, non-White populations (those of

European descent comprise 78 % of participants in genome-wide association studies [21]) blunts our understanding of the genetic mechanisms driving a myriad of other neurobiological factors.

The field of cultural neuroscience corroborates this need for neurobiological research in refugees. Recent findings have indicated that cultural background both contributes to varying symptom presentation and influences neural processing of information; for instance, differences in prefrontal activity during various tasks have been documented between those belonging to individualistic and collectivistic cultures [22,23], and amygdala response to emotional cues varies across cultural groups as well [24,25]. Despite this clear rationale for diverse neurobiological studies, a recent review of cultural neuroscience did not include any studies in Middle Eastern, Eastern European, South Asian, Latino, African, or Indigenous populations [22]—groups that encompass a high proportion of the global refugee population.

Some research groups have sought to address these knowledge gaps: for instance, an analysis of a longitudinal research study following Syrian refugee youth throughout a psychosocial intervention aimed to provide insight into research methods that support the integration of

biological, social, and cognitive data in humanitarian contexts [26]. Still, further insights are needed to improve the applicability of such methods across broad cultural, social, economic, and genetic contexts.

Given the relative lack of data and ever-increasing need for informed mental health resources and treatment for refugees, it is crucial that researchers are provided with the necessary tools for conducting equitable, effective research with refugee populations. Few published works have addressed this need, and those that have typically focus on specific cultural or ethnic groups [26–28]—as opposed to more broadly applicable strategies—or center on challenges related to the provision of clinical services [10,29,30], rather than those related to conducting research. In this paper, we discuss key barriers and methodological challenges to successfully and appropriately working with refugee and internally displaced communities, many of which have likely contributed to the relative lack of biopsychosocial research in this area. We detail practical recommendations for overcoming each of these challenges, often sourced from our experiences conducting multi-year studies and interventions for refugee mental health and working with communities serving diverse groups of refugees (see Table 1). Finally, we discuss the role of the research team in regard to cultural competency and partnering with the refugee community.

2. Challenges and recommendations

2.1. Challenges related to navigating cultural differences

Though cultural considerations are vital in most—if not all—of the research activities discussed herein, there are several potential cultural differences that warrant specific attention. Often, the cultural background of resettled refugees is unique from that of their host countries; thus, standard research tools and methods of the host country may lack validity or feasibility for refugee groups. Psychological measures, for instance, may not be culturally relatable across various backgrounds [31]. To illustrate an example, in our ongoing work with refugees from Syria and Iraq, we have found high non-response rates for items on the PTSD Checklist for DSM-5 (PCL-5; a 20-item self-report measure that assesses symptoms of PTSD) related to dissociative symptoms, as compared to the general population. Under such circumstances, it is possible that cultural factors impact participants' understanding of described symptoms on such measures and/or contribute to true low prevalence of certain symptoms in certain cultural groups (e.g., we have also found lower prevalence of somatic symptoms in refugee children from Syria as compared to those from Iraq [32]), thereby impacting validity. Also of note, for cultures or individuals preferring oral communication, common research practices of translation and back-translation of written measures that are then read by participants may be less favorable than having researchers ask questions aloud in an "interview" format [31]. Additionally, cultural variation has been documented in relation to symptom expression [32–35], as well as emotional expression [28,33,36]—thus, endorsement of scale items probing symptomatology may be qualitatively different depending on cultural background. These issues become most prevalent when using measures not validated in populations of applicable cultural backgrounds.

Another cultural consideration is the level of comfort when answering various questions. For instance, stigma surrounding mental health issues may be stronger in Arab cultures [37]. Difficulty sharing emotions, for example, has been documented in Arab American women [28]. Different social norms and religious beliefs may also exist regarding the discussion of certain topics, age-appropriate questions, or gender roles [38–41]. Sudanese participants, for instance, may be uncomfortable or offended if asked to discuss domestic violence [42]. Based on our team's experience in the field, questions related to sexual histories are, in some cultures, considered inappropriate for adolescents. Additionally, underreporting of sexual assault may be more prevalent depending on cultural background [42]. This intersection of comfort

level and cultural norms may also vary depending on the gender of participant and researcher [40]. Immigrant and refugee women from several cultural groups (e.g., Somalian, Syrian, Iraqi) have reported discomfort discussing health or mental health with male researchers or providers, for instance Refs. [38–40].

Social interaction and communication in a general sense may also be heavily influenced by cultural variation. For example, in a study of healthcare providers' experiences working with Somali women resettled in Finland, female nurses discussed initial discomfort (due to Finnish norms regulating clinician and patient behavior) when Somalian patients expected hugging from them [39]. If unaddressed, these differing social expectations have the potential to damage rapport. Past experiences and beliefs about health care may also differ and contribute to discrepancies in how participants and researchers think about medical concepts. Refugee research participants have shared feeling that healthcare providers in the U.S. expect them to know more than they do (e.g., how to read a thermometer), leading to uncomfortable interactions for participants [43]. Additionally, participatory research involving leaders from various immigrant communities has emphasized that Western ideas regarding what constitutes science may clash with other forms of knowledge (e.g., community, oral, traditional)—and if not discussed openly, may contribute to lack of trust in Western scientific methods [44].

Finally, language and literacy barriers represent common challenges in working with refugee populations. Researchers within the host country may not speak or understand the native language(s) of participants resettling as refugees; further, speaking and comprehension skills on the part of either research team members or participants may not accurately reflect reading skills (e.g., ability to read and comprehend a self-report measure; ability to verbally relay written instructions to a participant). Lack of appropriate interpreters is a well-documented challenge in work with refugees and immigrants: often, these populations must rely on children or adolescents in the family to translate, many of whom do not understand scientific or medical terms used by researchers or providers [39,41]. It is also important to avoid assumptions that language is homogenous within a given ancestral group: for instance, refugees of Arab origin share the same Arabic language but have several different dialects. In our work, it became evident that documents we had translated by Iraqi Arabs did not align completely with the dialect of Syrian or Lebanese Arabs. Additionally, the choice to employ the formal, written form of a language or the spoken, typically more casual form may depend on context, participant characteristics, and research aims. The same concept applies to cultural considerations: not all who come from the Middle East share the same culture. Culture may also dictate preferences regarding how information is presented to participants. For instance, in an investigation of healthcare preferences with African immigrant women, participants indicated disliking provided healthcare brochures, as they preferred direct conversation with physicians and often could not fully understand the prepared literature [38]. Depending on their background, some participants may also be hesitant to disclose a lack of language fluency or literacy, due to embarrassment or cultural norms of respect and social hierarchies [43]. Same might apply to research procedures including complicated and long language of the consenting documents.

2.1.1. Recommendations

Several practices may be implemented to address these cultural elements. Regarding research tools and psychometrics, it is important to not only ensure that measures, procedures, and instructions are provided in an appropriate language, but to use measures that have been tested and validated, as well as procedures that are feasible, in a given population. In other words, it is crucial that items are not only translated linguistically, but also translate culturally and map onto intended latent variables. Broadly, this requires researchers to conduct validation studies of psychological measures in diverse cultures and populations, to facilitate future research aims with these groups. When resource

constraints allow, an inductive (or "bottom up") approach—in which constructs emerge from qualitative data sourced from a cultural group and are then used to create quantitative scales—is recommended over a deductive (or "top down") method in which scales are translated or modified [31].

Special attention to building rapport and trust is particularly vital when working with refugee participants—and may specifically aid in addressing cultural stigma towards mental health topics [39,40,44]. Awareness of culture-specific factors that may increase participants' comfort level is recommended; for instance, participants may be more comfortable discussing mental health concerns with a researcher of the same gender or cultural background. To this aim, anti-stigma and cultural competence training for researchers is also essential [29]. Additionally, partnering with in-country scholars of similar backgrounds to participants in designing research projects and procedures when possible is essential in supporting these aims.

Clear, detailed explanations of protocols and concepts during which participants' prior knowledge of concepts described is not assumed can minimize communication issues [38]. Using lay terms and examples throughout communication may also aid in addressing level of comfort during recruitment and data collection activities [28]. Moreover, for participants unaccustomed to discussing mental health, concrete examples may provide vocabulary with which to do so. Clearly explaining confidentiality and anonymity of data is also essential in creating a comfortable environment for participants to disclose personal information [28]. Finally, regarding topics that are taboo for certain populations to discuss, flexibility may be necessary; for instance, when it became clear in our work that asking about the sexual histories of adolescents was considered inappropriate, we omitted these queries from further data collection activities.

To address language and literacy barriers, perhaps most vital is the recruitment of researchers and research assistants with language and cultural fluency [28,29,40]. While the PI of our projects is of Middle Eastern background (Iranian), to avoid cultural assumptions and diversify our team on the ground collecting data, those involved in understanding and interpretation are recruited from a variety of Arabic ethnic backgrounds specifically from the same countries of our refugee population—some of whom were also refugees or the adult children of refugees— and from cultures relevant to our participant groups. Importantly, we do not involve researchers from outside of that community in fieldwork. This has not necessarily been a difficult task, as many multi-lingual Arab students and trainees have been motivated to join in research that is meaningful for them or their families on both a personal and humanitarian level. We have observed this strategy to be integral in reaching 90 % recruitment in our original cohort. During data collection, instructions and measures may also be provided with several language options, including languages common to the host country and to participants' country of origin. If an interpreter must be used, scheduling longer sessions may be necessary to allow ample time for ensuring accurate communication [43]. Avoiding assumptions regarding participants' literacy level (even for those who are verbally fluent) has also proven effective; for instance, researchers may elect to read questions out loud to participants, to ensure comprehension and effective communication. Additionally, this practice avoids pressuring participants to reveal their level of literacy in a given language. It may also be preferable to read measures out loud for cultures that rely primarily on oral communication, as well as to obtain both oral and written consent for these populations, as a written document may not hold the same meaning to them as it would for cultures that rely more heavily on written communication [31]. Encouraging questions and checking in on common concerns is also a useful strategy in mitigating pressure for participants to raise any issues of comprehension themselves. Notably, the presence of researchers who speak participants' language and understand their culture (among other rapport building strategies discussed in the following sections) has demonstrated a positive impact at every stage of the research process—from increasing participants'

feelings of trust to ensuring research activities do not take place on cultural holidays [38,40].

2.2. Differences in family dynamics

Dynamics in families resettling as refugees may differ from those of their host country. As in families of immigrants, generational differences often intersect with cultural factors to create unique language and cultural fluencies, as well as changing family roles (e.g., parents relying on children to translate, thus shifting responsibility and hierarchy within the family [39,41]. Depending on cultural background, different family members may expect to play specific roles in the decision to participate in research. In some Middle Eastern cultures, for example, the male is more often regarded as the decision-maker of the family; it is therefore essential to include fathers and husbands in recruitment, informed consent procedures, and most data collection activities—even if they are not participating in the study themselves [40]. Similar dynamics have been documented in Ugandan families [31]. Expectations regarding who will attend a data collection session may also vary; for instance, in clinical settings patients may attend appointments with multiple family members [39], thereby shifting confidentiality and privacy considerations.

When data is being collected from children, special considerations may also be necessary regarding the involvement of mothers and fathers in decisions about their children's research participation. Among other factors, some cultures do not allow for the collection of biological samples (e.g., hair, saliva) from babies or children [45].

2.2.1. Recommendations

To address the influence of diverse family dynamics on research activities, researchers should be well-equipped with culture-specific knowledge of the populations they plan to interact with. Knowing with whom to confer regarding the decision to participate in research—in addition to obtaining informed consent from all appropriate family members—is crucial to appropriate recruitment practices. During data collection activities, cultural knowledge and open communication with participants is equally important. For instance, with Arab participants, gender segregation norms suggest that participants may be less comfortable sharing personal information with male researchers [46]. Our group has observed that recruiting female research assistants of Arab ethnicity improves rapport and participant comfort—particularly when participants include mothers and their children [40]. We make sure to always have both male and female research assistants available at the home visits. In other cultures, such as within Nepali populations, involving researchers with the same marital status, caste, or rural/urban background as participants may also be relevant in strengthening rapport [47].

For many cultures—and considering the vulnerable position of refugee status itself—including non-participating family members in data collection activities as much as possible is also indicated. When collecting data from children, especially biological data, allowing parents or guardians to collect samples if that is their preference, promotes a sense of control and protection of the child. In our own data collection practices, we have found that asking parents to collect both their own and their child's hair and buccal swabs was beneficial to their sense of agency [40].

2.3. Lack of trust sharing sensitive information

Biopsychosocial research, by nature, involves the disclosure of sensitive information by participants. Combined with the vulnerable position many refugees inhabit while navigating a host country with potentially differing norms, languages, and protocols—after having left their home and communities—feelings of uncertainty and wariness towards personal inquiries may be heightened. Some displaced populations have reported low confidence and trust in medical

professionals, often due to feeling that their concerns were not taken seriously in their host country, frustration born from differing expectations between patient and provider, and/or prior experience with insufficient healthcare services in their country of origin [27,48]. As health care settings and biopsychosocial research involve considerably overlapping concepts, content, and environments, these experiences of distrust may extend to research settings. Indeed, lack of trust was a frequently cited challenge during recruitment of refugees in a study related to bullying and childhood sexual assault [28]. Many participants had never discussed these events previously and were particularly concerned with their level of anonymity, as well as who would have access to any information they disclosed. Acknowledging mental health symptoms or abuse may also lead to negative social ramifications within some cultures [28,38]; thus, participants may be especially concerned with confidentiality. Anxiety regarding drawing negative attention or consequences from outside the community to oneself, family, or social group may also contribute to hesitance in discussing mental health information or stressful post-migration experiences (e.g., participants may be apprehensive about offending researchers by discussing discrimination faced in the host country [42]), as well as concern regarding providing biological samples (e.g., worries that information obtained from these samples may be used against them or their family).

2.3.1. Recommendations

A trusting relationship is the deepest foundation of any human communication; research is not an exception. Building rapport, prioritizing participant comfort, and practicing thorough and ongoing informed consent procedures is essential. Rapport and alliance-building have been repeatedly cited by participants resettling as refugees as effective in addressing fears and increasing comfort—even to an extent in which typically culturally taboo subjects may be discussed [39,43,46, 49]. Ideally, the process of building rapport can begin prior even to recruitment, by partnering with community organizations already working with refugees. For example, our group initially partnered with culturally informed medical clinics providing basic health screenings to refugees upon their arrival in the U.S., where culturally and linguistically fluent physicians could offer patients the opportunity to join a voluntary research study [3,50]. If interested, participants were introduced to the researchers by their physicians, which contributed to building a network of trust and connection. We believe this is one important reason for our ability to recruit more than 90 % of those who were referred to us by their physician. Focus group research with leaders of Punjabi, Nepali, Somali, and Latin American immigrant communities has also emphasized initial meetings with participants and the importance of immediately beginning to build rapport [44]. Similarly, we have observed that having the same researchers or research assistants involved in recruitment also conduct data collection aids in building trust and reducing uncertainty for participants. One of the authors additionally noted that self-disclosure about similar experiences, such as talking about her own children with mothers participating in a study, built mutual interest and improved rapport during recruitment and data collection. Throughout all study activities, researchers can address participant concerns about anonymity and privacy by providing detailed descriptions of how information will be kept confidential at every stage of a given project, validating participants' concern, and offering reassurance regarding confidentiality procedures and data storage. Offering private rooms for in-person data collection, as well as the option to conduct data collection activities via phone or email for those wishing to remain completely anonymous, are also effective strategies [28]. Our team offers the option of collecting data at participants' own homes. Regarding biological data collection, offering the option for participants to collect their own samples at home using kits mailed by the researchers (when feasible) may also increase comfort levels.

Throughout all recruitment and data collection activities, informed consent should remain an ongoing process. Conversations regarding confidentiality and consent should—per participants' wishes—involve any family members that need or wish to be involved (e.g., husbands or fathers in Arab American families) and rapport should be built with them as well. As in healthcare settings, providing accurate, clear, and detailed information and explanations of procedures are key facilitators of trust [38,44]. Researchers should also openly invite and discuss any potential concerns or expectations (to avoid placing the burden on participants to bring up concerns themselves; [48], in addition to assuring participants that they may choose to withdraw from the study at any time. Particularly for groups that have experienced human rights violations by authority figures, the concept of "voluntary" research may not be fully understood as such [31,51]. Intentional emphasis on the voluntary nature of the research, including explicitly defining this concept during informed consent protocols, is advised. Finally, as part of the informed consent process, explaining to participants how the research aims to benefit immigrants, refugees, and their families, may moderate concerns regarding the purpose of data collection (e.g., whether the data will be used in a way that harms the participant or their community; [43]. For instance, knowing the research data might help in advocacy for their socioeconomic and healthcare needs and that of other immigrants, can help in building mutually beneficial alliance.

2.4. Political fears

Fears related to political or legal repercussions are another area of potential anxiety for people resettling as refugees. In addition to the abovementioned fears of stigma or social repercussions for sharing sensitive mental health information, it is common for those resettling as refugees to be wary of sharing information regarding immigration status. Many may be hesitant to disclose such information, for fear that it may jeopardize employment or their ability to remain in a host country. Indeed, displaced persons have cited fear of authorities discovering their immigration status as reasoning to avoid health insurance and even needed health care services [29]. In environments where lack of honesty towards immigrants by officials has been documented [31], it is likely that these events further contribute to fear and distrust towards those in positions of authority. It is plausible, then, that these concerns may extend to any attempt to gather information from refugees—including those of researchers. Research-related interviews, for instance, may resemble interviews conducted to determine participants' legal refugee status, therefore impacting perceptions regarding whether the research is truly voluntary and without legal repercussions [31,51]. During the Muslim ban era of US immigration policies, a concern of Middle Eastern refugees was what they disclosed in research could be used for their deportation from the country. Having originated from countries with negative experiences of authoritarian government may also color perceptions of the current context. When conducting research with refugee populations, these misgivings—albeit justified, and, one may argue, adaptive—could act as a barrier to gathering data. People resettling as refugees may be especially concerned about who may have access to the information they share, as well as the level of security of the collected data.

2.4.1. Recommendations

When conducting research with any population with reason to fear or distrust authority figures, it is a primary responsibility of the researcher to assuage these concerns and ensure that potential participants are appropriately informed. To neglect this responsibility will not only result in recruitment difficulties but may also engender unnecessary stress and fear for participants—an outcome that may arguably be classified as unethical treatment of human participants. Also in a situation of a lack of trust in how the collected data might be used, the provided data might not be accurate for the purpose of self-protection. It is therefore of utmost importance that researchers are conscious of the likelihood of political fears in refugee populations and are equipped to competently address them. This involves, firstly, an awareness of the laws and political climates in one's country or region that may impact

the experiences and sense of security of refugee groups to that area. The United Nations High Commissioner for Refugees (UNHCR) recently published the opinion that new legislation proposed in the United Kingdom, for example, will substantially increase barriers to citizenship for asylum seekers and refugees [52]. A post-migration environment with stricter policies may be more difficult and stressful to navigate than a host country with more amiable immigration policies; additionally, as anti-immigration policy has historically been racially linked, racial and ethnic background of refugee participants may moderate the effect of policy on their lived experience in a host country [53,54]. For these reasons, researchers must be aware of their current political climate and how it may influence the comfort and trust of refugee participants. As when addressing concerns related to mental health stigma, assuring participants of data confidentiality—as well as describing data security procedures in detail and encouraging questions—is essential. Offering the option to remain completely anonymous (i.e., by conducting recruitment and data collection by phone, email, or online) has also proven effective [28]. Regarding the use of information after data collection, researchers should also describe in detailed, layman's terms how the collected data will be disseminated to the public. Typically, data would be de-identified and shared only in aggregate; case studies, in contrast, would require special considerations and consent by the participant(s) involved.

Participants should also be assured that the information they share, nor the results of the study, will have any bearing on their legal status. In fact, it is recommended that researchers avoid asking about legal status at all. Though this may prove methodologically challenging—and indeed did in our own work with refugees—it is often possible to obtain needed information without explicitly asking about legal status. For instance, in our ongoing study, we sought to recruit both a group of refugees and a group of immigrants to serve as controls, to dissociate the effect of exposure to war from stress of migration. Asking about legal status would have been, perhaps, the simplest method of classifying these groups; still, asking such questions may have also seriously impacted participants' comfort level and the integrity of the data collection (e.g., higher non-response rates, increased measurement error in self-reports). Instead, subject matter experts—including researchers from the same cultural and ethnic background as our participants—determined alternative methods of classifying immigrants and refugees. This included consideration of participants' countries of origin and corresponding likelihood of war exposure, as well as screening questions related to why they left their country (e.g., "for work," "to escape war"). Notably, this methodological flexibility was facilitated by including researchers from the same cultural background as the study population.

A final strategy for addressing fears related to the political and legal implications of sharing personal information is to explain not only the protective measures taken by the researchers, but also any social justice aims of the research questions themselves. Participants should be made aware of the goals of the research and how the researchers hope to use the data collected to promote mental health equity and improve services available to refugees and their families. That is, explaining the intended benefits of a study is equally as essential as detailing the protective measures taken against any study risks. Finally, it is also important to assure that the participants are aware that lack of participation will not negatively affect their immigration status. As it was noted earlier, especially having come from authoritarian contexts, some participants might be afraid disagreeing to provide research data might be detrimental to their refugee status.

2.5. Challenges related to migration and resettlement

The logistics of transitioning to a new country or region also pose several barriers to conducting research with refugee populations. Various methodological challenges we have documented include difficulty reaching participants due to transitions post-resettlement, slower

than average rates of recruitment, and difficulty accessing data collection spaces for participants [28,40]. As many refugees will experience a period of ongoing transitions even after arrival in a host country, maintaining contact with prospective participants long enough to onboard them to a study and conduct data collection can be challenging, especially for longitudinal studies. Addresses, phone numbers, and frequented establishments (e.g., local clinics, places of worship) where recruitment procedures began may change, particularly early in resettlement. This may contribute to slow recruitment, as many initial contacts may be lost during this transitory period. Moreover, those who are recruited to a study may face subsequent difficulties participating, such as lack of childcare or transportation to data collection spaces.

2.5.1. Recommendations

Several strategies have proven successful in addressing these logistical challenges. To mitigate slow recruitment, we recommend planning during the early stages of a research project to obtain IRB approval for multiple forms of recruitment. For instance, recruiting both online and in-person (e.g., posting flyers in areas/establishments frequented by prospective participants) typically expands reach to a broader demographic. Similarly, ensure that initial contact with recruitment materials is positive: study advertisements should use approachable language, be culturally sensitive, and detail meaningful, but not coercive, compensation [28]. Once in touch with prospective participants, it is advisable to collect multiple forms of contact (e.g., phone, email, contact info for multiple family members, social media apps commonly used by participant groups) to reduce loss of participants to attrition throughout a project. Establishing and maintaining relationships with community organizations that work with refugees and keep databases of contact information is also recommended—and may indirectly contribute to increased rapport with participants as well.

Regarding difficulties accessing transportation or childcare in order to attend data collection sessions, best practices include offering data collection options that take place in the home or other locations already frequented by participants (e.g., schools, health clinics) when possible. For most forms of self-report data, home data collection is feasible; still, biological data may also be collected in the home. Indeed, many biological sample collection methods are easily adapted to in-home collection—some of which do not even require a researcher's presence. Mailable kits with easy-to-follow instructions are now available for collecting saliva swabs, passive drool samples, and blood samples, to name a few (e.g., Salimetrics SalivaBio oral swabs, Tasso blood collection devices; Salimetrics, State College, PA; Tasso, Inc., Seattle, WA). Additionally, recent technological advances have made in-home data collection of psychophysiological data such as recordings of skin conductance level (SCL) more feasible. The eSense app (Mindfield Biosystems, Inc., Berlin, Germany) and accompanying electrodes, for instance, travels easily with a researcher and can be used to collect mobile SCL data. Indeed, a recent investigation from our group indicated that this method is both effective and scalable [55]. When in-home or mobile data collection is not an option, however, researchers should aim to provide as flexible a schedule as possible when inviting participants to a lab space. For example, as many of refugee parents have less flexible work schedules, we offer data collection in the evening and over the weekends.

3. The role of the research team

In addition to implementing strategies for addressing methodological challenges, conducting research with refugee populations involves navigating a nuanced role as a researcher. 'Cultural competency' takes on new meaning, as researchers must not only be culturally sensitive to the norms of participants' home countries and backgrounds, but also to the experiences of forced migration and resettlement. Research may necessitate competence in working with participants from a wide variety of cultural backgrounds (many of which are not well-represented in

psychiatric research [5,56]), all of whom are also affiliated with the refugee community and the culture it entails. This unique intersection of identity and experience must be considered by researchers seeking to work with these groups, thereby supporting both accuracy of data and conclusions, as well as adherence to ethical principles of human subjects research. For instance, investigators in the U.S. should avoid extrapolating methods from White or Black populations [41]—both of which are better represented in research than many ethnic and racial groups experiencing forced displacement (though the literature remains heavily biased towards White populations [56])—onto work with refugees. As discussed, recruiting researchers and research assistants of the same backgrounds as participants aids in centering informed voices that may draw attention to cultural factors outside the scope or consideration of other study personnel. Other members of the research team may then also obtain first-hand opportunities to observe and improve their cultural competence. Still, this recruitment practice—though essential—is not always sufficient: nuances other than shared cultural or linguistic background influence these dynamics. For instance, in the context of reproductive health research, the recruitment of unmarried Nepali women from urban areas to work with Nepali women from rural backgrounds was not effective, as women from rural areas did not trust that unmarried Nepali researchers could understand their experiences with motherhood [57].

When working with displaced populations, it is also recommended that researchers focus on forming partnerships with the refugee community and organizations that serve refugees on the ground [30,44,53]. Indeed, recent work outlining research priorities for working with groups impacted by humanitarian crises emphasizes collaboration among researchers, clinicians, policy-makers, and participant communities, as a means of enacting system-wide, sustainable intervention [58, 59]. Aligning with and working in tandem with in-country stakeholders such as medical health clinics, non-profit organizations, schools, local scholars, local social media groups, religious organizations, and other institutions aimed toward providing resources and support to refugees fulfills mutual goals. For instance, researchers may gain access to a broader participant pool and maintain contact with them more easily, and trust may be more readily built when participants are introduced to researchers and study opportunities by organizations they already trust. Forming these networks allows for the transfer of rapport from non-research-related environments to research settings (e.g., by meeting prospective participants via involvement in a local community event, researchers may begin to establish rapport prior even to recruitment), as well as equipping research teams with the knowledge required to offer further benefits to prospective participants (e.g., by making referrals to educational/occupational opportunities, healthcare professionals, and other resources within these partnered networks). Of note, the efficacy of these partnership efforts requires not only cultural, but structural competence—i.e., an understanding of inequities in systems, institutions, and social circumstances that may influence participant groups [60]. To reference the most recent example, referrals to unaffordable healthcare settings or inaccessible job opportunities, for instance, may damage rapport rather than strengthen it.

Research partnerships may be initiated by reaching out to local community leaders (e.g., within religious organizations, refugee support organizations, etc.) to discuss the goals of research projects [26], using social media to identify community events, and contacting schools and universities with programming specific to supporting refugee students, among other outreach activities. Research teams may also collaborate with local businesses within participant communities: for example, a study of stress biomarkers with Syrian refugees partnered with local hairdressers to collect hair samples, while offering free haircuts to participants [61]. Finally, at the conclusion of any research project, considering how findings may be promptly circulated back into the community (e.g., via consultations with schools, community/religious leaders, and/or local scholars; sharing recommended intervention designs) for their own use is essential in maintaining equitable

relationships [62].

Forming long-term relationships with participants is also mutually beneficial. Specifically, we have also observed participants turning to researchers as resources for non-study-related needs—e.g., participants may ask researchers for referrals to health professionals, about local facilities and grocery stores, or other basic needs of persons new to a host country. By nature of the experience of forced migration and resettlement, researchers joining with the refugee community may be asked to fulfill these roles—and being prepared to do so may further increase rapport between participants and the research team. An additional benefit of focusing on partnering with participants and communities is an increased sense that research is not being done "to" or "on" them, but "with" them. That is, participants are considered equal partners in the work, as opposed to subjects. The same attitude should also apply to non-profit, non-research organizations that agree to assist with research projects, despite their already overwhelming burden of responsibilities. This ethos may be further expressed by sharing resultant findings with participants and their communities (as they likely will not have access to academic journals [30]), as well as sharing data with the community for use in developing interventions, improving resources, co-writing publications, or seeking funding. Finally, establishing effective partnerships may be achieved through efforts towards collaboration and co-publication with in-country scholars (e.g., by initiating contact via email, social media, or at conferences; remaining informed on work released by other scholars in the field; etc.). These strategies not only help to foster continuous, trusting, and mutually beneficial alliances, but also increase the impact of the research beyond only the production of academic science.

Finally, collaborating with refugee communities via community-based participatory action research (CBPAR) methods when feasible is similarly recommended. This methodology extends the ethos of partnership by forming a non-hierarchical research team comprised of both researchers and participants [62]. Within this structure, participants may, for instance, be involved in identifying research topics relevant to their community, preparing research materials (e.g., consent forms, scale translations, etc.), and making decisions regarding how findings are disseminated. Nevertheless, despite the benefits of CBPAR, the nuances of relevant cultures, structures, and realities must still be considered. Recent findings have highlighted the potential challenges to CBPAR posed by inter-/intra-group conflict and structural inequalities, as well as the potential for attempts at CBPAR to worsen said inequality [63]. In the presence of existing social or political hierarchies, for example, inviting communities to participate without attention to these dynamics risks providing yet another environment (i.e., the research project) for powerful figures to dominate or coerce other members of their community. Researchers must, therefore, familiarize themselves with community power structures and assess the feasibility of CBPAR (e. g., through power-mapping analyses to identify hierarchies and distribution of power/influence within a community) prior to enacting these methods [63].

4. Conclusions

The need for biopsychosocial research in displaced populations and proportional lack of data has been well-established. In this paper, we intended to address this need by offering methodological strategies and practical recommendations for future research. While much of the emphasis herein is centered on gaining cultural competencies specific to the cultural/ethnic group participating in a specific research project, many methodological challenges when working with refugees are similar across these groups. Informed by our own experiences after eight years working with these populations, we aimed to provide guidance that not only encourages future research in an underrepresented population, but empowers investigators in logistically carrying out this work. We also hope this work will aid researchers in stepping into this realm with cultural and structural competency—practices crucial to

addressing existing humanitarian crises. With the increasing global population of refugees, research that can further psychological and psychiatric understanding and intervention is becoming ever more necessary— calling for competency, creativity, and flexibility in addressing these inherent challenges and working towards greater research representation for people resettling as refugees.

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