

Refugees and internally displaced populations

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5.3.1 Learning objectives

To understand the following key aspects of research with refugees and Internally Displaced Persons (IDPs):

1. The nature and characteristics of refugees and IDPs;
2. Ethical concerns surrounding migration research and approaches to address these;
3. Linguistic and cultural challenges facing refugees and the critical role of interpreters when conducting research or providing care;
4. Mental health issues of refugees and IDPs in different settings and appropriate and ethical research methods to address their needs;
5. Importance of evidence-based interventions to properly manage acute conditions and the challenges of conducting research among refugees or IDPs with acute conditions.

5.3.2 Introduction

The traditional role of the health sector during emergencies and disasters is response-focused on addressing and managing a single hazard. The Health EDRM framework requires the active collaboration and participation of an array of sectors and stakeholders across different levels of society to implement an approach focusing on the full spectrum of hazards, including but not limited to natural, biological, technological, and societal (1). A consequence of these hazards is forced migration, which is discussed in this chapter.

Populations who have been forced to flee their homes and lands are heterogeneous in nature, and have complex reasons behind their displacement, and the destination of their fleeing journey (2). Armed conflict, financial circumstances, disasters caused by natural hazards, and a lack of sufficient resources are all reasons behind forced migration. Refugees are individuals who reside outside the country of their nationality due to a well-founded fear of persecution based on their race, religion, nationality, membership of a particular social group or political opinion (3).



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IDPs represent those who have been forced to leave their homes and lands due to conflict, violence, disasters, or resource insecurities, but remain inside the internationally recognized borders of their home country (2). At the end of 2017, there were an estimated 40 million IDPs and nearly 20 million refugees globally (3–4). It is worth noting that, due to their location or circumstances, it can be more challenging to provide humanitarian support to IDPs than to refugees, which makes IDPs one of the most vulnerable populations around the world (4).

Evidence-based research includes collecting, analysing, and implementing best available evidence to enhance the decision-making process (5), improve the provision of health care and provide scientific evidence for Health EDRM programmes. This chapter discusses four specific topics to consider in evidence-based research among refugees and IDPs: humanitarian ethics, language and interpretation, mental health and acute care.

5.3.3 Humanitarian Ethics

Refugees and IDPs have been forcibly uprooted from their lands and cultures. Therefore, scholars argue that investigating and understanding their living conditions is an act of social justice. These populations continue to experience vulnerability and structural violence due to race and ethnicity, legal status and identity, as well as socioeconomic status and linguistic difficulties. Although migrants may benefit from participating in research that improves their health and wellbeing (6), it is the responsibility of researchers to ensure that their investigation is conducted under humane conditions and using ethically-sound approaches.

Alongside the more general issues of ethics in Health EDRM discussed in Chapter 3.4, conducting research among refugees and IDPs carries the potential for specific ethical concerns that may arise especially during or after emergencies and disasters. Linguistic and cultural barriers may lead some refugees to engage in research without understanding its objectives, outcomes and possible risks. The variation in power between refugees and researchers might drive these vulnerable individuals, out of fear or illiteracy of their rights, to engage in research involuntarily. Furthermore, research carries the risk of causing harm to refugees and IDPs if certain population-specific considerations are not properly addressed. For example, if the investigation is conducted in a low- or middle-income country in which refugees are temporarily residing without the same rights or equal treatment as regular citizens, the privacy of their personal information might not be protected, and their safety might be unknowingly jeopardized. Indeed, refugees might be exploited, persecuted and deported should their legal status be compromised due to ongoing or previous research.

Conducting research that involves direct engagement with humans requires following certain ethical practices, such as obtaining an informed consent (Chapter 3.4). The principle strategies of informed consent are disclosure, comprehension, capacity, voluntariness and consent (7). Ensuring the integrity of these four strategies while obtaining an informed consent from refugee and IDP participants may be challenging. Refugees may have limited language skills and high illiteracy rates, making it difficult or unfeasible to adequately inform them about the research procedures or to require them to read and sign informed consent forms. The

heterogeneity of health literacy levels between and within refugee populations could affect the process of explaining the outcomes of the research they intend to be involved in, and any adverse effects of their involvement should these arise. Research personnel who lack adequate cultural sensitivity training may also be unable to appropriately inform refugee participants about the nature of the research, which could thereby compromise the integrity of the informed consent process.

Before starting a research study among refugees and IDPs, researchers should comprehensively assess the benefits of undertaking the study for this specific population, the participants undergoing the assessment and the society as a whole. They also need to recognize the importance of protecting the confidentiality and privacy of their participants. Essential identity and demographic data such as names, dates of birth and current residences should only be collected when the benefits of this procedure far outweigh the harms. If such data are collected, anonymization or pseudonymization procedures should be used to protect participants and ensure their confidentiality. Hard copies should be kept in secure areas and personal data should be safeguarded by comprehensive safety systems or separated physically from other collected materials. All electronic files should be encrypted and protected by passwords, and access to these files should be limited to personnel who are conducting the particular research study.

Finally, the leaders of the research have the responsibility of adequately training their staff and interpreters to use culturally sensitive approaches when explaining the nature of their research and to conduct the informed consent and data collection processes adequately, while avoiding any cognitive biases that might affect the quality of the research.

Case Study 5.3.1

Example of important cultural issues in a research project with Syrian refugees in Lebanon

A doctoral student was undertaking a qualitative migration research project as part of her dissertation. She planned to go to Lebanon and conduct semi-structured interviews with Syrian refugees to understand their lived experiences during a transitional period.

Upon arrival in Lebanon, she recruited an Arabic-speaking research assistant to help with the field work and the interpretation processes, but the assistant voiced concerns about privacy and confidentiality. She recognized why collecting names of participants might jeopardize their privacy and safety. She made the ethically-sound decision not to collect their names and decided to perform a sex- and gender-based analysis instead.



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5.3.4 Language and interpretation

Language and cultural barriers disrupt communication between medical practitioners and refugees, limiting their access to and maintenance of treatment, increasing their use of emergency services, and reducing their health-related quality of life. Caring for refugees is challenging due to the complexity of their communication barriers, health conditions and their limited health system literacy (8-11). Limited local language proficiency may lead to poorer treatment adherence (12), impede refugees' access to fundamental services and life necessities such as housing (13), and negatively impact their social capital, because the majority find themselves unable to reach out and extend their social networks beyond those who speak their mother tongue (14). In Canada, limited local language proficiency was associated with a rapid decline in the health status of newly arriving refugees and other immigrants (15). Some of these communication difficulties are related to cultural differences and possibly fear of physicians (16). Emergency practitioners, however, can mitigate the harms of communication barriers experienced by refugees through enhancing the appropriateness of the health care they provide (17-18).

High-income countries have attempted to implement interpretation services within their social and healthcare systems to aid refugees and other migrants with poor language skills. This approach helped refugees access, navigate and maintain social and healthcare services (19). Interpreters act as a liaison between both ends of the conversation and play a pivotal role in overcoming language barriers. They should possess certain attributes that are fundamental to their role, such as the ability to fluently communicate in the native tongue of the refugee as well as the official language of the healthcare or social service provider. Furthermore, evidence shows that medical interpreters should receive proper training in medical terminology and interpretation to ensure the quality of their work (20). Interpreters should not take a central role of the conversation but rather maintain their position of support to the quality and accuracy of this interaction. It is preferable for them to have background or cultural resemblances to that of the refugee so that they are able to understand and properly interpret the indirect gestures and expressions which could be specific to this background or culture. However, local interpreters are very likely to be recruited from the same community as the study participants, a practice that could bias the interview process and give rise to confidentiality concerns and misinterpretations generated by cultural assumptions or taboos. Finally, interpreters should be trained on the importance of respecting the confidentiality of their clients and the application of procedures that protect their privacy and the privacy of the information they exchange.

In the field of migration research, using interpreters can improve the quality of the evidence. In qualitative research (Chapter 4.12), interpreters narrow the gap between the perceptions of refugee participants and the understanding of the researchers conducting the investigation. In quantitative research, interpreters facilitate the exchange of data from and to refugee participants. However, there are several limitations to using interpreters in migration research. For example, certain refugee or IDP populations might have an unconscious mistrust of locally recruited interpreters and would be suspicious of any enquiries, which might make

them feel uncomfortable about participating in research. Moreover, the lack of human and timely resources may impede the data collection process, and therefore the quantity of interpreters becomes a determinant to the quality of the research. The accuracy of interpretation may also affect the quality of evidence, mainly because verification of responses is limited. Finally, interpreters could allow their cognitive biases to interfere in the process of exchanging information, which, in return, affect the quality of the data collected.

5.3.5 Mental health research

Disasters and humanitarian crises negatively impact the mental health status of affected populations (Chapter 5.1). Mental health problems could be the result of pre-existing illnesses, emergency-induced disorders or conditions caused by the humanitarian response to disasters. Therefore, a sound and effective response to a health emergency or disaster should consider addressing, investigating and managing the mental health conditions of affected populations. Refugees and IDPs who experience or witness traumatic events or violence before their resettlement are at a higher risk for developing mental health conditions such as depression, anxiety or PTSD (21-23). Such events could have been witnessed or experienced before fleeing (when individuals have to give up their properties, jobs, education, as well as family and social networks), during their migration journey (when some may be faced by precarious events and substandard living conditions), or after their arrival to the host country (where they may undergo prolonged asylum-seeking processes, stigmatization, and barriers to accessing their fundamental life needs) (13, 24).

Conducting mental health research among refugees or IDPs poses several challenges that must be addressed adequately to ensure the proper conduct of research among these vulnerable populations. Firstly, the physical environment surrounding refugee participants might be inadequate or unavailable to conduct research. Secondly, some researchers may resort to employing the services of family members as interpreters. This practice gives rise to ethical concerns because family members cannot be objective interpreters, especially when discussing frequently stigmatized issues such as mental health problems. Thirdly, the limited time availability of refugees and IDPs because of work or family health issues could lengthen the research process and require further funding. Furthermore, investigating past traumatic events by regular research staff or interviewers may cause some participants to relive these events, which could ignite their psychiatric symptoms and cause them harm (25). Lastly, externally validating or “generalizing” the findings of mental health research to broader refugee or IDP populations is challenging because those who are willing to participate in a study examining their mental health problems may be radically atypical of the wider population.

Multiple procedures must be followed when conducting research among refugees or IDPs. Researchers must ensure that their research is performed in a secure and quiet setting with adequate privacy measures that the participants feel comfortable about. Offering participants a monetary compensation for their time should not be the sole reason for



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their participation in research without understanding its nature. Therefore, declaring the provision of any financial or other incentives for participation should occur after explaining the research procedures and outcomes intended. It may be beneficial for researchers to explore proxies for psychological distress, such as sleep disturbance or decreased social functionality, especially in cultures where mental health problems are highly stigmatized. Moreover, when applying for funding (Chapter 6.3), researchers should explain that the process may take longer than expected, leading to a need for more funding to ensure the completion of the proposed study. All interview procedures must be concise and preferably conducted somewhere close to the participant's residence. Lastly, professional psychologists or physicians with expertise in dealing with trauma-induced mental health conditions must be present during the questioning process to ensure the proper management of acute mental health symptoms should they arise.

When conducting research using existing studies, systematic reviews and meta-analyses represent the most feasible and accurate approach to consider when dealing with this vulnerable population (Chapter 2.6). A systematic review is a research methodology that aims to identify, critically appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a research question (26). Meta-analyses usually accompany systematic reviews and provide more clear-cut and explicit estimates of the effects of studied interventions (27). However, conducting systematic reviews may present some challenges: the process is time consuming and may not be suitable for answering a question that has not yet been studied. Furthermore, the accuracy and certainty of findings depend heavily on the searches done by the reviewers' and the quality of the studies they review.

Case Study 5.3.2**Use of a systematic review to assess psychosocial services and programmes for refugees and IDPs (28)**

There is a large body of literature on psychosocial services and programmes. However, evidence on the effectiveness of these interventions among refugees and asylum seekers is sparse and not adequately quantified. Therefore, Nosè and colleagues (28) conducted a systematic review and meta-analysis on the effectiveness of such services.

To ensure a robust and systematic review of literature, they set inclusion criteria that answered their research question and defined the population, interventions, comparisons, and outcomes of interest. They searched for controlled trials of adult refugees and asylum seekers in high income countries that had compared the effects of a psychosocial intervention versus no intervention, usual care, or minimal interventions, to assess post-traumatic and depressive symptoms.

The findings showed that psychosocial interventions such as narrative exposure therapy (NET) were effective in decreasing PTSD symptoms as well as depressive symptoms compared to control groups. However, these findings are limited to adult refugees and asylum seekers in high-income countries and cannot be generalized to IDPs, migrant children, or refugees in low- and middle-income countries. Furthermore, the definition of refugees differed across studies, which could camouflage certain population specificities that should be considered.

The inability to generalize findings due to population heterogeneity may limit the evidence-informed decision making process. Therefore, groups such as the Grading of Recommendations, Development and Evaluation (GRADE) recommend decreasing the certainty of evidence should researchers detect any indirectness affecting the effectiveness of a certain intervention (29).

5.3.6 Acute Care

Although refugees and migrants are likely to be in good health prior to fleeing, their health status might be jeopardized while in transition or living in substandard conditions after departure from their homes and lands (24). The interaction of overcrowded environments, contaminated water, poor sanitation and low access to health services such as vaccination serves as a breeding ground for illnesses to re-emerge. Communicable diseases make up almost 90% of consultations in refugee settlements (30). Diphtheria is an example of a vaccine-preventable disease with rare occurrence rates, even in low- and middle-income countries. The pathogen behind diphtheria, however, has spread among Rohingya refugees in Bangladesh due to their congested and overcrowded living conditions, and the lack of vaccination coverage among them (31). Cholera is another example of an opportunistic water diarrhoeal disease that spread among Yemeni children because of limited access to clean water and sanitation resources (32-34).

Managing acute conditions among vulnerable populations requires evidence-based interventions that are proven to be rapid and effective.



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New research among refugees and IDPs with acute conditions should only be undertaken if it addresses a critical issue with high prevalence among this population, and assesses a research question that a review of existing research or data does not provide an answer to (Chapter 3.6). Research protocols must be well designed to reflect the logistical and ethical challenges of conducting research among refugees and IDPs, as well as the proposed practices to ensure the success of techniques such as randomization (Chapter 4.1) and recruitment among patients with acute conditions. Moreover, protocols must describe, in detail, the use of privacy methods to ensure the confidentiality of participants in an emergency environment.

When conducting the investigation, researchers must acknowledge the critical physiological and cognitive conditions that refugees and IDPs might experience. Their condition might mean that they are in pain, frightened, unaware of their rights within a new healthcare system, illiterate of their health conditions, or unable to explain their symptoms due to language barriers. They might also have impaired cognition, preventing them from giving an informed consent. Refugees and IDPs may also think that treatment is contingent to their participation in the research study. The researcher, therefore, must have sound and culturally appropriate communication skills to help inform potential participants about the nature of research, the benefits and harms of undergoing it, and their right to refuse participation without any penalty. If capacity to provide an informed consent is jeopardized due to cognitive impairment, the researchers must obtain an “a priori” approval from an ethics board or committee to employ other methods of consent-acquiring processes such as proxy, prospective or deferred consent (Chapter 3.4). Nonetheless, researchers must always act in the best interest of the participant. Lastly, equity considerations must be addressed and strict rules must be imposed to prevent researchers, interpreters, or outcome assessors from discriminating against participants based on their gender, ethnicity, religion, sexual orientation or political opinion.

Case study 5.3.3 Identifying acute health needs in refugees and IDPs (35)

Refugee populations frequently move together in large heterogenous groups. These groups will often reach a political border or face a natural barrier that will lead to the formation of a temporary camp. The United Nations High Commissioner for Refugees (UNHCR) plays a major role in supporting the road, tent and health infrastructure for these camps. Nonetheless, the sub-standard living conditions and congestion in these camps is a risk factor for developing acute illnesses and conditions.

Rapid needs assessment surveys (Chapter 2.1) can play an important and timely role of mitigating acute health conditions. These detect the demographics of the populations, pregnant women, elderly, young children and cases of acute diarrhoea and acute respiratory infection or other communicable disease outbreaks. Multiple survey tools now exist online such as EPI Info from the US Centers for Disease Control and Prevention (CDC), which provides support for researchers and public health professionals as they prepare the questionnaire, enter data and conduct rapid analysis (36). Most rapid surveys are done in collaboration with local staff.

Hurricane Katrina forced many families to move from their homes into other cities, such as Denver, Colorado. Ghosh and colleagues conducted a rapid needs assessment survey to identify and examine the acute and contextual medical and non-medical needs of these populations that moved following the hurricane. Certain unique needs emerged, such as the necessity to educate individuals on the high altitude of the city of Denver, and what they can do to overcome altitude-related symptoms (35).

5.3.7 Conclusions

Conducting research for refugees and internally displaced populations can be rewarding both for vulnerable migrants and for health practitioners. Although research engagement can bring evidence-based practices and programmes for migrant specific conditions, researchers need to be vigilant for any ethical concerns that may arise. Training research staff on cultural sensitivity and adapting a comprehensive and explicit informed consent process are good practices to follow when conducting research with vulnerable populations. Field research for mental illness and acute care conditions should only be undertaken when the need for such investigation outweighs any potential harms. Knowledge syntheses such as systematic reviews and meta-analyses may improve the precision of research, reduce bias and limit unnecessary harms to local populations.

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5.3.8 Key messages

- o **Researchers need to consider population-specific ethical concerns when conducting research among refugees or IDPs, such as obtaining a comprehensive informed consent.**
- o **The linguistic barriers that refugees face require the services of interpreters when providing care or conducting research. Researchers need to acknowledge the confidentiality challenges and cognitive biases that may arise when using interpreters and work to overcome them.**
- o **Refugees and IDPs are at a disproportionately higher risk of psychiatric disorders. Mental health research among these vulnerable populations is challenging and requires ethical research methods.**
- o **Efficient management of acute care conditions among refugees and IDPs requires evidence-based research. Researchers should be transparent when planning their research and should have sound communication skills to explain its nature to refugees and IDPs.**

5.3.9 Further reading

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